

#### 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.



## ARBOR RESEARCH ANNUAL REPORT | 2013

### Dear Friends,



Our top priority is reducing the burden of chronic disease and improving the delivery of care to patients. As we grow as an organization, we seek opportunities to make meaningful improvements in patient lives and health care practices.

Building international partnerships strengthens our ability to reveal meaningful differences in clinical practice. The **Dialysis Outcomes and Practice Patterns Study** (DOPPS) now includes over 20 countries in its longitudinal survey of dialysis practices (pg. 6-7). The **Peritoneal Dialysis Outcomes and Practice Patterns Study** (PDOPPS) will launch this year after successfully partnering with researchers in the United States, the United Kingdom, Canada, and Japan (pg. 12).

These partnerships lead to important findings, which we strive to put into the hands of decision-makers. The **DOPPS Practice Monitor** (DPM) continues to provide timely data on clinical trends as dialysis facilities adjust to federally mandated changes in reimbursement for dialysis care. One of our newest projects, **Empowering Patients on Choices for Renal Replacement Therapy** (EPOCH-RRT), will gather information from patients with kidney disease in order to develop a web-based tool to aid patient decisions about treatment. For more information about these projects, please see pages 2-3.

Our diverse portfolio of projects also includes work to improve the delivery of health care through the analytic support of policy development. The past year has seen the expansion of information about dialysis facilities that we deliver via the DialysisReports.org website under the **ESRD Quality Measures** and **ESRD Quality Incentive Program** (QIP) contracts with the Centers for Medicare & Medicaid Services (CMS) (pg. 4). We have also welcomed new investigators to our interdisciplinary team this year. You can read more about our breadth of expertise on pages 2-3.

Design and management of research coordinating centers represent an area of increasing strength for Arbor Research. These projects require a full range of expertise including project management and support, data management and security, scientific input and oversight, analytic design, and clinical monitoring. The latest data coordinating center (DCC) to come to Arbor Research, funded by the National Institutes of Health (NIH) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), is the **Symptoms of Lower Urinary Tract Dysfunction Research Network** (LURN) DCC. LURN is developing patient-reported outcome measures and phenotypes for people with lower urinary tract dysfunction; the project has research collaborators at six clinical sites across the United States. The scope of the **Renal and Lung Living Donors Evaluation Study** (RELIVE) DCC was expanded under a new 2-year grant awarded to Arbor Research from NIDDK. Please read more about these projects on pages 8-9.

Yours sincerely,

Robert M. Merion, MD, FACS

President, Arbor Research Collaborative for Health

## 2013 | ARBOR RESEARCH ANNUAL REPORT

## INTERDISCIPLINARY

## MAGIC

## CREATING A COLLABORATIVE HOME FOR RESEARCHERS

There's interdisciplinary magic at Arbor Research. Every day, teams of clinicians, biostatisticians, epidemiologists, and health care economists confer over complex medical problems. Supporting their efforts are programmers, application developers, project teams, editors, and information technology staff, each with specialized knowledge. This breadth of expertise, blended in the right sequence and with careful timing, is a powerful tool for exploring research questions that demand insight and discipline.

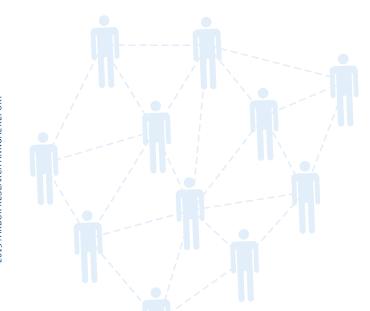
A case in point is the **DOPPS Practice Monitor** (DPM), an initiative of the **Dialysis Outcomes and Practice Patterns Study** (DOPPS). The DPM website (DOPPS.org/DPM) provides objective surveillance of clinical trends as dialysis facilities adjust to federally mandated changes in reimbursement for dialysis care. Using information from more than 100 representative US dialysis facilities, the website displays

800 figures and tables that provide comparisons and trends over time. To make this happen requires an intricate set of activities — facility recruitment and training; data collection, integration, and cleaning; analysis, review, and graphics development; website production; then finally dissemination of findings through Web conferences, media releases, and journal publications.

Breadth of expertise, blended in the right sequence and with careful timing, is a powerful tool for exploring research questions that demand insight and discipline.

On a smaller scale, technical expert panels, coordinated by Arbor Research to develop quality measures in support of Medicare end-stage renal disease policy, involve experts from institutions across the country. Organizing that expertise into productive discussion groups requires the efforts of clinical and scientific investigators from Arbor Research and the University of Michigan, as well as analysts, project support staff, and data managers.

At the head of these initiatives are investigators, and Arbor Research is committed to developing the careers of its newest researchers. Joining Arbor Research within the past year are Laura Mariani, MD, MS, and Elizabeth Cope, PhD,

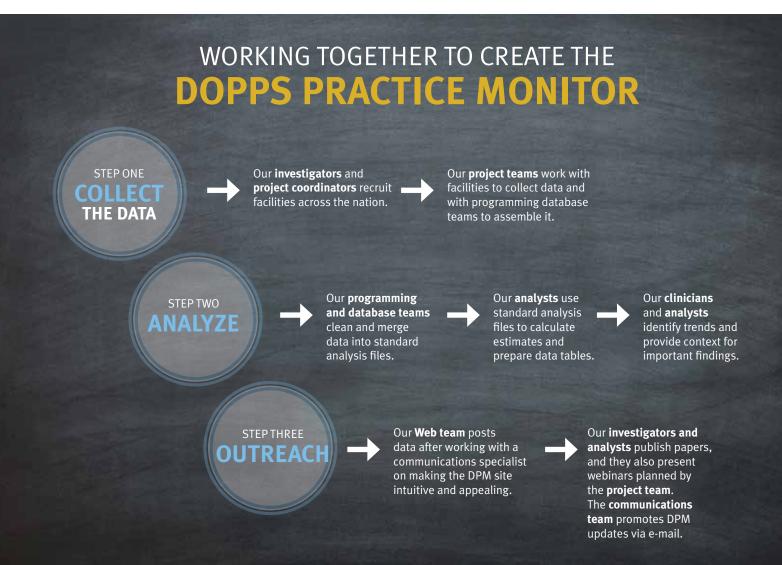


MPH. Dr. Mariani is a nephrologist and researcher with a focus on glomerular disease progression. Dr. Mariani holds an individual fellowship grant from the National Institutes of Health (NIH) to study the management of patients with nephrotic syndrome. Dr. Cope's research interests include racial and socioeconomic disparities in health care and outcomes, as well as geospatial analysis. Francesca Tentori, MD, an investigator at Arbor Research for the past 6 years, is the recipient of a career development award from the NIH.

Recently, Dr. Tentori was the recipient of one of the awards granted by the first cycle of the Patient-Centered Outcomes Research Institute funding mechanism. The project — Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) — was one of 25 selected from among nearly 500 applicants. To identify factors that matter most to patients with kidney disease and to study how they are affected by different types of

dialysis, Dr. Tentori reached out to multiple partners: four from the University of Michigan (the Center for Statistical Consultation and Research, the Department of Health Behavior & Education at the School of Public Health, the Center for Bioethics and Social Sciences in Medicine, and the Division of Nephrology in the Department of Internal Medicine) and four beyond Ann Arbor (the National Kidney Foundation of Michigan; the Henry Ford Health System/ Greenfield Health Systems; the American Association of Kidney Patients; and the National Kidney Foundation). Patients are also partners, through contributions to the patient-centered perspective of the proposal and ongoing involvement in the EPOCH-RRT patient advisory panel.

"I'm looking forward to working with our many partners and to building collaborative relationships with patients affected by advanced chronic kidney disease and their families," said Dr. Tentori.



## Putting analysis to work:

Providing objective and actionable support for policy implementation

High quality data wedded to expert clinical and scientific knowledge are critical for implementing best practices in the delivery of care for patients with chronic diseases. The availability of this information is vital for many: health consumers making decisions about where to receive care; providers who are dedicated to providing the highest quality of care; and federal policy makers who must make informed decisions about the allocation of resources for health care. The exciting challenge in this era of increasing and sophisticated information is harnessing quality and reliable data and expertise, and then disseminating it to consumers, providers, and decision-makers. Arbor Research has a proven track record of clinical and scientific expertise, technical skills that support rigorous analysis, and the production of timely data reports.

Arbor Research maintains the DialysisReports.org website, developed in 2009 for the purpose of efficiently disseminating performance data and information to support the Centers for Medicare & Medicaid Services (CMS) quality programs for end-stage renal disease. This website was launched under contract with CMS

in 2009. The website continues to serve as the vehicle for distributing data reports, allowing facilities to preview their Dialysis Facility Reports, Dialysis Facility Compare (DFC) quality measures, and since 2011, their QIP scores. The development and maintenance of this website complements the goal of quality improvement by providing dialysis facilities with a mechanism to obtain important information on how they perform on a range of clinical outcomes and process quality measures. The website also allows facilities to seamlessly and instantly submit comments or questions about their data reports.

In January 2012, CMS launched the first national level value-based purchasing program, the **End-Stage Renal Disease Quality Incentive Program** (ESRD QIP). Arbor Research supported the implementation of the ESRD QIP. Facility QIP performance scores are derived from performance on specific measures of the quality of care delivered to patients. Arbor Research calculates the performance scores and associated payment reductions for all Medicare-certified dialysis facilities. The scores are made available in the performance score reports.

DialysisReports.org, maintained by Arbor Research, is CMS's system of record for securely delivering reports and certificates for the QIP for PY 2012-PY 2014, as well as for conducting a data preview period for dialysis facilities.

Once scores are finalized by CMS, each facility receives a performance score certificate for posting. The preview period for facilities for the first year of the QIP, Payment Year (PY) 2012, was held July 2011.

DialysisReports.org is CMS's system of record for securely delivering reports and certificates for the QIP for PY 2012 – PY 2014, as well as for conducting a data preview period for dialysis facilities. During the private 30-day preview period of their data reports, facilities log in to the secure website to view their scores and submit clarifying questions and one formal inquiry, before scores and associated payment reductions are finalized by CMS. As part of its role in policy implementation, the website is also the official source for the measure definitions and specifications of measures published by CMS in the Federal Register for the respective National Proposed Rule Making Process (proposed rule) and the Final Rules for QIP PY 2012 – PY 2015.

DialysisReports.org supports policy implementation through the distribution and preview of the performance score report data; preview of public reporting measure data; technical measure specifications for quality measures identified in the proposed and final rules for QIP. The effect of these implementation activities has the potential to support providers and improve the quality of care delivered to patients. Providers can use these performance data in ways that can enhance the quality of care, for example, using measures results to further develop their own internal continuous quality improvement strategies. The reports also provide valuable information to CMS about the effect of quality measures they have implemented in their various programs such as QIP and DFC. By sharing data, health care providers can see the outcomes of the care they provide, government can offer timely oversight, and patients can enjoy better health.

#### What is available on DialysisReports.org?

#### **DIALYSIS FACILITY REPORTS**

DFRs privately available to facilities and networks

DFRs, appended with comments, available to state surveyors and CMS Region Representative via DialysisReports.org

State and Region profiles available

#### DIALYSIS FACILITY COMPARE

DFC preview reports privately available to facilities and networks – comment period for 1 month

DFC updated with publicly available data quarterly

#### QIP PERFORMANCE SCORE REPORTS/ PERFORMANCE SCORE CERTIFICATES

Draft PSRs privately available to facilities – comment period for 1 month

Final PSRs available to facilities. PSCs available to download and print

Data publicly available via CMS website

TECHNICAL EXPERT PANEL REPORTS

METHODOLOGY USED TO PRODUCE THE REPORTS

#### SPECIFICATIONS FOR

QIP Measures Quality Measures Dialysis Facility Compare Measures

# CULTURAL FOCUS ON INTERNATIONAL PRACTICES BENEFITS PATIENTS EXCENSION OF THE PRACTICES PATIENTS EXCENS

The diversity of culture around the world makes travel exciting and challenges us to look at ourselves in new ways. Culture likewise influences the care for chronic disease. The **Dialysis Outcomes and Practice Patterns Study** 

The **Dialysis Outcomes and Practice Patterns Study** (DOPPS), which examines variation in hemodialysis practices in over 20 countries, gathers data to reveal the practice patterns that result in the best patient outcomes. The strength of our international approach to large-scale longitudinal studies depends on identifying variation in practices around the world, thus creating a natural experiment that benefits patients across the globe.

Beginning in 2013, the DOPPS will launch in Turkey and Russia. This expansion builds on more than 15 years of successful international research for the DOPPS and will provide important insights to improve care in these countries.



Differences in health care policies between countries often lead to differences in treatment for patients on dialysis. The DOPPS captures and analyzes data to demonstrate the effects of policy change. In 2006, Japan changed its policy for reimbursing dialysis facilities for erythropoiesis-stimulating agents (ESAs); the DOPPS was able to demonstrate changes in ESA doses, intravenous iron

The strength of our international approach to large-scale longitudinal studies depends on identifying variation in practices around the world, thus creating a natural experiment that benefits patients across the globe.

use, and hemoglobin levels that occurred shortly after this policy change. Similarly, when the policies for reimbursing dialysis facilities in the United States changed in early 2011, the DOPPS launched the **DOPPS Practice Monitor** (DOPPS.org/DPM) to present timely data on trends in clinical practices. By tracking trends in patient data before and after the policy changes and comparing similar trends and experiences across countries, the DOPPS provides detailed and precise information about the specific effect of policy change.

Over the years, the DOPPS has highlighted differences in vascular access as a major driver of differences in clinical outcomes between countries. More recently, we have highlighted important differences in dialysis session length, which is now shorter in the United States than in most other DOPPS countries. Policy again plays a role, with reimbursement policy changes in Germany and Japan leading to longer dialysis session times there. In contrast, the United States has no performance measures directly linked to dialysis session length. Dialysis frequency has also been a topic of interest in countries recently added to the DOPPS. At the most recent meeting of the American Society of Nephrology, the DOPPS presented research on dialysis frequency in Saudi Arabia and China. Describing these differences in treatment and analyzing the effect these differences have on patient outcomes will highlight unwanted variation and lead to better information about the best way to treat patients with renal disease. ■



DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY

Australia Oman Bahrain Qatar Belgium Russia

Canada Saudi Arabia

China Spain
France Sweden
Germany Turkey

ItalyUnited Arab EmiratesJapanUnited KingdomKuwaitUnited States

**New Zealand** 



#### DATA COORDINATING CENTERS AT ARBOR RESEARCH

With projects underway at four data coordinating centers (DCCs) at Arbor Research Collaborative for Health, DCCs are models of collaboration. Arbor Research's multi-disciplinary team offers a full menu of expertise, including data management and security, scientific input and oversight, analytic design, and clinical monitoring. The DCC provides a project management nexus that creates a collaborative infrastructure to produce innovative research.

1

The **Dialysis Outcomes and Practice Patterns Study** (DOPPS) (hemodialysis), **PDOPPS** (peritoneal dialysis), and **CKDopps** (non-dialysis chronic kidney disease) are international prospective cohort studies of nationally representative samples of patients and practices. Each study involves international collaboration on a very large scale, with Arbor Research serving as the DCC. The DOPPS, ongoing since 1996, is the longestrunning of these studies and now follows 500 dialysis facilities in over 20 countries. With co-investigators in each country, the DOPPS DCC uses the same data collection protocol despite multiple languages and cultures. DOPPS investigators have produced 148 manuscripts in peer-reviewed journals worldwide.

Currently in its second study phase, the Adult to Adult Living Donor Liver

**Transplantation Cohort Study** (A2ALL) DCC is a collaboration between Arbor Research and the University of Michigan and is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Consisting of nine clinical centers in the United States and Canada, plus the DCC, this multi-center research consortium gathers data about the outcomes of living liver donation. The A2ALL DCC team has developed a barcoded biosample tracking and management system to reliably link biosamples and DNA with subjects' clinical data. The study has 103,824 samples from 2,386 subjects stored at the NIDDK Biosample and Genetics Repositories to be used by investigators for current and future research. At the end of this study phase, the consortium will have collaborated for 12 years. Its investigators have produced 21 manuscripts.



3

#### Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN)

is a consortium consisting of six clinical sites and the DCC. The group is developing patient-reported outcome tools and deep phenotyping of patients with lower urinary tract dysfunction (LUTD), identifying biomarkers, and collecting and storing biosamples and DNA at NIDDK repositories. The consortium's goal is to characterize the different types of LUTD experienced by women and men in order to help develop targeted treatments to improve the lives of patients.

The **Renal and Lung Living Donors Evaluation Study** (RELIVE), a collaboration between Arbor Research and the University of Michigan, is a National Institute of Allergy and Infectious Diseases-funded multi-center research consortium studying outcomes of living kidney and lung donation. The project consists of the DCC and five clinical sites. Over the past 8 years, the study has produced the largest cohort to date of individually studied living kidney donors, covering a time period of nearly five decades. The study team has leveraged its expertise to secure additional funding to perform novel analyses on the existing study data set to test whether kidney donors experience a higher incidence of death, end-stage renal disease, and other comorbidities compared with matched controls.

This new phase of the RELIVE study improves on past research on living kidney donors by using merged data sets from the National Health and Nutrition Examination Study and the National Death Index, and claims data from the Centers for Medicare & Medicaid Services (CMS). Most previous studies of long-term outcomes after living kidney donation compare living kidney donors with the general population. In contrast, Arbor Research will now be able to use files that are rich in clinical data, making it possible to eliminate data from patients with conditions that would have ruled them out as kidney donors; instead, a comparison group very similar to actual kidney donors from the RELIVE study can now be constructed. This novel control group will allow us to better assess whether living donation increases the long-term risk of kidney disease or associated morbidities such as cardiovascular disease.





Saurabh Patel and Shannon Li

**TEAM PROFILE** 

### DATA SERVICES

High-quality research relies upon high-quality data that's appropriate to the policy question. The Arbor Research data management team provides many services: data collection and study management, integration and adaptation of existing data sources for research, and displaying and communicating research results. Doing so leverages the team's technical expertise in health care informatics, analytic programming, data architecture, and the system development life cycle.

Most important to its success, however, is the data management team's close collaboration with investigators, project management, and analytic teams. Throughout each project, these teams work together to ensure that the data on which our studies are based are reliable, interpretable, and pertinent to the question at hand.

While designing an expansion of the **ArborLink** data collection software to include chronic kidney disease and peritoneal dialysis patients, data and applications experts met with clinical, project, and analytic staff—not just from Arbor Research but also among international collaborators. The team sought to ensure an understanding of how alternate treatment modalities were used in different cultures and how "usual activities" among caregivers lend themselves to different data collection tools. These discussions

led to refinements of study protocol and the evolution of data collection instruments to capture research goals. This provided the data management team with the background needed to support ongoing analyses for the project.

Collaborative understanding and day-to-day interaction allow the data management team to help identify needed study management tools.

This collaborative understanding and day-to-day interaction allow the data management team to help identify needed study management tools. Software developed by Arbor Research supports the implementation of projects, and programmers can often be heard asking "how about if we made a tool to...?" Management of data collection instruments, and their translations in 11 languages and 19 countries, has always posed a challenge for the **Dialysis Outcomes and Practice Patterns** (DOPPS) team. Identifying this challenge, programmers and project team

members designed and implemented a new application to allow the project support team to directly edit and proof questionnaire contents online, which can then seamlessly flow into the online data collection tools. By promoting consistency and automated tracking of the correspondence between data fields among multiple languages, this application makes the questionnaire implementation process faster and more efficient, and the validation process more reliable.

This approach also contributes to the success of the ESRD Quality Incentive Program (QIP) project, which implements value-based purchasing for dialysis facilities. This project requires the extraction of close to a terabyte of data on Medicare claims from a mainframe system to produce data files for analysis. It requires the programmers to have a thorough knowledge of the data to help support analysts in their work. Arbor Research database and analytic programmers worked with mainframe specialists to integrate different technologies, making use of various strengths to carry out the project. In the implementation of system development life cycle controls for the integrated process, more efficient and automated quality checks were developed specifically for the large volume of data at each step in the process.

It's the people on the team who make the difference. Shannon Li, director of data services, explains, "Our programming team combines top-notch technical skills with a strong dedication to understanding project context and proposing better solutions. That combination is hard to beat!"





#### RESEARCH INTO ACTION: Tracking chronic kidney disease

When the Centers for Disease Control and Prevention (CDC) sought a provider to complete a partially finished website, they identified a crucial necessary skill: the ability to combine technical expertise with a collaborative research approach. The website and data services teams at Arbor Research fit the bill.

Released in fall 2012, the website is a public face of the CDC's national program monitoring chronic kidney disease (CKD) and progress toward CKD-related HealthyPeople 2020 goals. It shows about 200 different indicators of the incidence, prevalence, treatment, and awareness of CKD in the United States, along with research methodology, key points and explanations, and related resources. (To view the site, click on cdc.gov/ckd, then select the CKD Surveillance System spotlight link.) After the contract award in 2011, Arbor Research began working within the constraints of the inherited website framework, focusing on ironing out functional problems and working with research teams to identify priorities for later development. In finishing the site, the Arbor Research team untangled the previous contractor's code and aggregated data from multiple sources for the inaugural release of the site. More importantly, the collaborative relationships fostered with information technology staff at the CDC, as well as with nephrology researchers from the University of Michigan and the University of California, San Francisco, form the basis for the ongoing expansion of site capabilities. With the website now public, the Arbor Research website development team is immersed in the next step, an upgrade to improve the site's functionality through more innovative design.

## **BUILDING ON SUCCESS**

### DOPPS BRANCHES INTO PERITONEAL DIALYSIS AND CHRONIC KIDNEY DISEASE

Arbor Research is committed to advancing information about the practices that lead to the best outcomes for patients with chronic disease. Leveraging the infrastructure and design of an existing success can yield additional results that quickly find their way into practice. Recently, two new Arbor Research projects have gotten a jump-start on quickly improving patient lives.

Building on the successful model of the **Dialysis** Outcomes and Practice Patterns Study (DOPPS), Arbor Research is launching the Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS) in 2013. Like the DOPPS, the PDOPPS is multinational, examining peritoneal dialysis practices in Canada, Japan, the United States, and the United Kingdom, with anticipated inclusion of additional countries soon. The overarching goal of the PDOPPS is to understand those practices that minimize early discontinuation of peritoneal dialysis while maximizing patient survival and quality of life. Patterning itself after the original DOPPS, the PDOPPS will seek to establish a network of investigators across multiple countries, drawing upon DOPPS-tested work for study protocols, management tools, data collection instruments, and analytic approaches.

Peritoneal dialysis is a home-based form of renal replacement therapy that does not require the patient to make frequent visits to the hospital or dialysis facility; it may be associated with improved patient satisfaction and

quality of life. While hemodialysis is the more prevalent modality in the United States, a greater proportion of patients in Canada and the United Kingdom are successfully treated with peritoneal dialysis.

Compared with facility-based hemodialysis, peritoneal dialysis has been demonstrated to be a more cost-effective form of treatment, and patients using this technique enjoy similar survival as do those on hemodialysis. Moreover, patients on peritoneal dialysis typically take fewer medications than hemodialysis patients. To maximize the success of peritoneal dialysis, patients need to be engaged in their own care and acquire skills in self-management. Because the technique is performed at home, patients must be vigilant against infection and other treatment-related complications. Unlike hemodialysis, one of the major challenges in the management of patients on peritoneal dialysis remains treatment-related complications over time that require a transfer to hemodialysis; this occurs in a large proportion of patients on peritoneal dialysis. A major focus of the study will be to understand those factors that lead to early and premature discontinuation of peritoneal dialysis therapy.

The DOPPS study team at Arbor Research has had a longstanding interest in peritoneal dialysis. "No study of dialysis is complete without a study of peritoneal dialysis, which is on the rise, particularly in developing nations," says Justin Albert, Arbor Research DOPPS project manager.



Jeffrey Perl and Bruce Robinson

Building a strong partnership with the International Society for Peritoneal Dialysis (ISPD) has been essential to launching the PDOPPS. When he was president of ISPD, Dr. Simon Davies made the partnership to develop the PDOPPS a major goal of his leadership of the society. Together, the DOPPS researchers and ISPD leadership have developed relevant study hypotheses and data collection instruments, a formal research agenda, and a platform to support local efforts for country-specific funding and recruitment.

## "[The PDOPPS] will have a major impact on the improvement of quality in care and clinical outcomes for patients treated with PD."

 Simon Davies, past president of the International Society for Peritoneal Dialysis

Similarly, the **Chronic Kidney Disease Outcomes and Practice Patterns Study** (CKDopps) examines international practice variations in the treatment of chronic kidney disease (CKD). Beginning in 2013, the CKDopps will launch in Brazil, Germany, and France, with subsequent launches

planned for China and the United States. Partnerships with investigators and stakeholders around the globe have made the launch of the CKDopps possible: In Germany, a network of nephrologists led by Dr. Werner Kleophas has implemented a registry to monitor the course of CKD, and will launch CKDopps using that infrastructure this year. In France, Dr. Benedicte Stengel is leading a major new initiative to identify optimal practices for CKD patients in a partnership that includes the French renal registry. Dr. Roberto Pecoits-Filho and Dr. Antonio Lopes are leading the launch of CKDopps Brazil, in partnership with the Brazilian Society of Nephrology.

Past expertise in developing global research for the DOPPS will contribute to the successful launch of the PDOPPS and CKDopps. ArborLink software will be used to collect data and manage each study. Already in use for the hemodialysis study, this software offers real-time data validation and study management tools and is adapted for each language and medical culture.

With the right partners, experience, and tools, the team of investigators will shed light on the best practices for new patient populations. With data and findings from each of these related studies, practitioners caring for patients with kidney disease will gain a wealth of knowledge to improve patient lives.

#### **HOW ARBOR RESEARCH**

## learns + teaches



Nephrology (ASN), Arbor Research not only contributed a wealth of information, but also learned from fellow experts.

#### BEHIND THE RESEARCH

Preparation for these meetings involves extensive teamwork. Prior to presentation, abstracts, posters, and talks undergo rigorous scrutiny in-house. Analysts and other team members spend hours preparing data and material for public presentation. A prime example of this diligence is the DOPPS presentation at ASN 2012 in San Diego, California. There, the DOPPS program presented 16 accepted abstracts and conducted a standing-room-only DOPPS Symposium with data on over 12,000 dialysis patients worldwide.

An integral part of the Arbor Research mission statement is the company's commitment to provide and maintain current information on best practices. A substantial and growing body of published research papers, along with informative resources such as the **DOPPS Practice Monitor** (DPM) and the quarterly dialysis facility reports for the Centers for Medicare & Medicaid Services (CMS) provide evidence of this commitment. These initiatives are achieved by reaching out to collaborate with other researchers and organizations, resulting in relationships that span globally from the Institute for Healthcare Policy and Innovation at the University of Michigan in Ann Arbor to the Abu Dhabi Health Services Company conference in the United Arab Emirates.

Attendance at over 50 scientific meetings and conferences in 2012 created many opportunities for Arbor Research staff to engage in productive discussions with an international range of health care experts and to pool knowledge about supportive health practices. With representation at major meetings such as the European Renal Association – European Dialysis and Transplant Association Congress, the Healthcare Information and Management Systems Society conference, and the American Society of

Arbor Research staff attended over 50 scientific meetings and conferences in 2012, creating opportunities to engage with health care experts from around the world.

Abstracts such as those presented at ASN often evolve into published papers. On ArborResearch.org, many resources are available to support clear communication with diverse audiences and effectively share information among researchers, clinicians, and patients. Plain language summaries of the research are offered for many published papers so that everyone interested in learning — patients and caregivers alike — is able to understand the research topic. Research slides are included with the intention to enhance understanding and to supplement other research work. Efforts like these continue to help Arbor Research share and learn from the best and the brightest.



#### **ASIA**

Chinese Association of Blood Purification Management of Chinese Hospital Association Conference, Changsha, China

JDOPPS Annual Meeting, Japan

3rd Asia Pacific Colloquium, Seoul, Korea and Shanghai, China



#### 2012 CONFERENCES & MEETINGS

#### **UNITED STATES**

American Society of Transplant Surgeons, Florida

Healthcare Information and Management Systems Society (HIMSS), Nevada

2012 Consensus Conference, Virginia

Annual Dialysis Conference, Texas

American Health Information Management Association (AHIMA) ICD -10 Conference, Maryland

National Renal Administrators Association, Washington, DC

American Nephrology Nurses Association, Florida

Centers for Medicare & Medicaid ESRD Quality Measures Clinical Technical Expert Panels meeting, Maryland

National Kidney Foundation Spring Clinical Meetings, Washington, DC

American Transplant Congress, Massachusetts

Academy Health Conference, Florida

American Association of Kidney Patients, Georgia

ESRD Network Forum Quality Conference, Maryland

Society of Research Administrators International meeting, Florida

American Society of Nephrology 2012, California



#### **EUROPE**

European Renal Association - European Dialysis and Transplant Association Congress, Paris, France

European Dialysis and Transplant Nurses Association/European Renal Care Association, Strasbourg, France

International Society of Nephrology, Copenhagen, Denmark

German Nephrology Congress, Hamburg, Germany

UK Country Meeting, London, England

Global Clinical Nephrology Advisory Board, Zurich, Switzerland

#### **UNITED ARAB EMIRATES**

Abu Dhabi Health Services Company (SEHA) Conference, Abu Dhabi

Middle East Society for Organ Transplantation (MESOT), Abu Dhabi

#### BRA7II

Brazilian Society of Nephrology, Sao Paulo





Arbor Research's 2012 financials reflect our growth and stable financial position. Contract and grant revenues of \$15.8 million, from a diverse set of 14 publicly-funded and 10 privately-funded projects, represent a 17% increase over the prior year. The growth in revenue enables us to expand our mission with commensurate increases in expenses and project activity. The balance sheet is supplemented by strong investment returns, bringing total net assets to \$12.6 million, an annual increase of 12%.

Assets	2012	2011
Cash and cash equivalents	7,309,158	7,160,663
Certificates of deposit and investments	10,697,245	10,165,865
Grants and contract receivables	5,732,807	1,824,394
Prepaid expenses and other assets	240,924	335,515
Property and equipment, net	879,929	898,930
Total assets	24,860,063	20,385,367
<b>Liabilities and Net Assets</b>	2012	2011
LIABILITIES		
Accounts payable and accrued expenses	2,575,044	1,902,386
Deferred revenue	9,677,520	7,195,165
Total liabilities	12,252,564	9,097,551
NET ASSETS		
Unrestricted	12,597,468	11,282,066
Temporarily restricted	10,031	5,750
Total net assets	12,607,499	11,287,816
Total liabilities and net assets	24,860,063	20,385,367

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTA
REVENUES	UNKLSTRICTED	TEMIT ORAKILI KESTKICTED	TOTAL
Grants and contracts	15,760,351		15,760,35
Donations	,,	4,281	4,28
Net investment earnings (loss)	1,296,682	,, -	1,296,68
Other income	5,782		5,782
Loss on disposal of property and equipment	(855)		(855
Total revenues	17,061,960	4,281	17,066,24
EXPENSES			
Program services	13,628,619		13,628,61
Supporting services	2,117,939		2,117,93
Total expenses	15,746,558		15,746,558
Change in net assets	1,315,402	4,281	1,319,68
Net assets, beginning of year	11,282,066	5,750	11,287,81
Net assets, end of year	12,597,468	10,031	12,607,499

#### ARBOR RESEARCH COLLABORATIVE FOR HEALTH

#### **BOARD OF DIRECTORS**

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