

2014

IMPROVING PATIENT LIVES THROUGH RESEARCH AND DATA ANALYSIS



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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# Dear Friends,



At Arbor Research, we are driven by a strong sense of mission. That mission is to improve patients' lives through research that shapes medical policies and practice. In the past year, we created a strategic plan to guide our growth and ensure we maintain our focus as we expand our staff and our portfolio of research projects over the next several years.

Two of our newest projects speak directly to one of our six strategic imperatives: a sharp focus on patients as key stakeholders in research. Both of these exciting projects are funded by research contracts with the Patient-Centered Outcomes Research Institute (PCORI): Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) and the NephCure Kidney Network. Along with several of our data coordinating center projects, this work focuses directly on the experiences of patients. You can read more about these projects on pages 2-3.

Building national and international partnerships strengthens our ability to conduct research in new areas of clinical practice. On page 4, we take a look at three recent examples: the United States Renal Data System (USRDS), the Pelvic Floor Research Group, and the Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN).

Our partnerships with dialysis researchers around the world have helped the Dialysis Outcomes and Practice Patterns Study (DOPPS) Program grow. The DOPPS now collects data in over 20 countries. The Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS) launched this year and is collecting data in three countries. The Chronic Kidney Disease Outcomes and Practice Patterns Study (CKDopps) has begun data collection in France, Germany, Brazil, and the United States. More information can be found on page 5.

Our increasingly diverse research portfolio includes continuing work to improve the delivery of health care through the analytic support of policy development. This year, Arbor Research won a 5-year competitive renewal to maintain our role as a Measure and Instrument Development and Support (MIDS) contractor, one of only 18 organizations to be awarded this designation by the Centers for Medicare & Medicaid Services. We are pleased to continue and expand our work to conduct analyses that inform federal health care policy makers. On pages 6-7 you can read about this work, and our DOPPS Practice Monitor, a private sector-funded tool that presents data on the effects of health care policy changes.

Finally, we broadly lay out our plans for the future and our efforts to give back to our community on pages 9-11. The people who work at Arbor Research have created a culture of excellence that is evident in everything we do! That sets us apart, and I am incredibly proud to work alongside such a dedicated team of professionals.

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*

# Focus on Patients

Providing objective and actionable support for policy implementation

If you ask the staff at Arbor Research what drives them, they will tell you it is our mission to improve the lives of patients. That strong sense of mission is what motivates us every day to reveal the patterns that lead to better care and to design systems that improve the delivery of care. Few patients may read our papers or know our names, but they are always on our minds as we work to discover new information and put our research into practice.

Expanding our portfolio in the area of patient-centered research, the Patient-Centered Outcomes Research Institute (PCORI) awarded two new contracts to Arbor Research this year. PCORI is an independent, non-profit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed health care decisions.

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Patients are always on our minds as we work to discover new information and put our research into practice.

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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, and will ensure that the study addresses the questions of greatest relevance. Already, we have interviewed over 180 patients about which outcomes matter the most to them. Interview responses



*Senior Research Scientist Dr. Francesca Tentori (center) gives a presentation on the EPOCH-RRT project.*

are being analyzed and will inform a patient questionnaire to assess the impact of dialysis modality (hemodialysis and peritoneal dialysis) on factors that patients have identified as important among participants in the **Dialysis Outcomes and Practice Patterns Study (DOPPS)** and the Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS). Information gathered through patient interviews and questionnaires will inform the development of a decision aid tool that will assist patients facing the choice of dialysis modality.

The second contract from PCORI will allow Arbor Research, in partnership with the NephCure Foundation, to develop and expand the **NephCure Kidney Network**. The diseases collectively referred to as nephrotic syndrome (focal segmental glomerulosclerosis, minimal change disease, and membranous nephropathy) are rare but serious kidney diseases that pose a substantial physical, psychological, and financial burden for those affected. They often lead to kidney failure, requiring dialysis or other major medical complications. The NephCure Kidney Network will enable important clinical and patient-reported data on nephrotic syndrome to be contributed, under patient control, to a centralized repository. The rich clinical and patient-reported outcomes database, with patients as active participants, will facilitate rapid development and

*Project Assistant Sherrie Turner and Project Coordinator Michelle Maxim.*

execution of comparative effectiveness research to benefit patients with nephrotic syndrome.

Additionally, new work in our data coordinating center (DCC) program area brings new opportunities for research that improves patient lives. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) recently awarded a grant to Arbor Research and the University of Michigan to serve as the DCC for a multi-center, 5-year cohort study of glomerular disease patients called **CureGN** (cure glomerulonephropathy) will include a larger sample of patients and longer follow-up than prior studies of these relatively uncommon but important kidney diseases.

Consistent with our goal to embrace patients as key stakeholders (see page 10), we have also sought new ways to enhance our existing research projects with patient-reported outcomes. As the DCC for the **Symptoms of Lower Urinary Tract Dysfunction Research Network** (LURN), we are working to develop and test patient-reported tools to quantitatively describe the symptoms of lower urinary tract dysfunction in women and men. The network is also working to understand adaptive behaviors, such as changes in diet and activity level, that people use to reduce or cope with their symptoms. These efforts will inform strategies to prevent and manage disease and improve the lives of patients who suffer from lower urinary tract dysfunction. ■

*Research Scientists Elizabeth Cope and Laura Mariani.*



## Getting the Word Out

We love to share news about our work.

Staying connected to our partners and other stakeholders is essential to putting our research into action. We send our e-mail newsletter to a growing list of interested readers. Each issue of the newsletter contains information about our most recent publications and research findings, project milestones, and upcoming events.

Social media helps us reach even more people with similar interests. We share news about our organization and our research via Facebook, Twitter, and LinkedIn. Please visit [ArborResearch.org](http://ArborResearch.org) to sign up for our newsletter and connect with us online. ■





building

# partnerships

## Our Role in the Research Community

Arbor Research was built on the principle of building partnerships in pursuit of better research. In fact, we're proud of saying "Collaborative" is our middle name. We are fortunate to have research partners at a wide range of institutions across the globe.

Based on the strong reputation of the Data Coordinating Centers (DCCs) at Arbor Research, we have found new opportunities to partner with external researchers. We recently embarked on a new collaboration with the University of Michigan, to provide data management and analytic support to the Pelvic Floor Research Group. Researchers from the **Pelvic Floor Research Group** work with Arbor Research on the **Symptoms of Lower Urinary Tract Dysfunction Research Network** (LURN).

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### "Collaborative" is our middle name.

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A strong partnership with the University of Michigan resulted in a successful bid for the **United States Renal Data System** (USRDS) contract funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The USRDS is a national data system that collects, analyzes, and distributes information about end-stage renal disease in the United States. As part of the collaborative effort to serve as the USRDS data coordinating center, we will conduct research using Centers for Medicare & Medicaid Services (CMS) claims data and Web-based reporting of renal data. Selected data from the **Dialysis Outcomes and Practice Patterns Study** (DOPPS) will be used as an additional source of highly detailed national clinical and patient-reported data, as well as for international comparisons. Building on a lengthy record of peer-reviewed publications and collaborations, we will contribute to the USRDS annual

report, as well as contributing original research for new publications.

The **DOPPS** reached new partners this year through a new online guide to partnering with the DOPPS Program. This guide, which can be found at [DOPPS.org/ForResearchers](http://DOPPS.org/ForResearchers), invites investigators with novel questions and proposals for new studies to collaborate with our team. This will maximize the scientific value of the wealth of data made possible by all the participating facilities and patients.

Conferences provide an additional venue to share ideas with like-minded researchers. Arbor Research is proud to present abstracts and symposia at scientific meetings throughout the year. ■



*Project Coordinator Chris Pustulka at the DOPPS booth at the National Kidney Foundation meeting in April 2013.*



## »»» DOPPS GROWS AROUND THE WORLD

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

Russia and Turkey recently joined the **Dialysis Outcomes and Practice Patterns Study (DOPPS)**, with data collection beginning in both countries in September 2013. Investigators and members of the DOPPS project team have been actively involved in training and the launch of the study in these countries. In addition, the DOPPS and the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) have partnered to support the study and extend research collaborations in Europe.



*Russian Country Investigator Boris Bikbov and Senior Research Scientist Ron Pisoni at a DOPPS meeting in Russia in March 2013.*

The **Chronic Kidney Disease Outcomes and Practice Patterns Study (CKDopps)** is designed on the model of the original DOPPS. This prospective clinic-based cohort study is based on observing the practices used to treat patients with chronic kidney disease and identifying those variations in care that yield optimal patient outcomes. With the aid of our international study partners, the study is officially underway in Brazil, France, and Germany, as well as in the United States where data collection launched in early 2014.

The **Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS)** is designed to reveal optimal practices for peritoneal dialysis patients worldwide. The PDOPPS pilot study was completed in Canada in 2013 and has been followed-up with the launch of the longitudinal cohort study in January 2014 in Canada and the United States. Funding for the study has been secured through various governmental and private organizations to support international data collection efforts. Data collection will expand in 2014 to include representative facilities in Japan, Australia, and the United Kingdom. ■

## ArborLink



*Programmers Michael Lipham and Greg Wirth.*

In order to respond to the specialized needs of our data coordinating centers, the team at Arbor Research developed a data collection and study management instrument known as ArborLink. Originally created for the Dialysis Outcomes and Practice Patterns Study in 2002, this software platform has been continuously updated to keep pace with ever-changing research requirements. ArborLink is now used in 22 countries, with forms and surveys translated into 19 different languages. It currently houses many years of longitudinal data on more than 70,000 study subjects.

Each implementation of ArborLink starts with a core set of features, and is then specifically adapted to meet the unique needs of the study. The software combines innovative features such as real-time data validation and study management tools. Our multidisciplinary collaboration among users, clinicians, analysts, and study monitors provides invaluable insight for IT staff adapting the software to the unique needs of each project. ■

*CKDopps Investigator Antonio Lopes and Distinguished Research Scientist Friedrich Port.*



# Information for Sound Decision-Making

Our work to improve care for patients with chronic disease extends beyond research on clinical practice. Impartial investigation to develop health care policy improves the delivery of care and leads to better outcomes for patients. We work to provide thoughtful analysis and monitoring of data that serves policy makers.

As part of our efforts to inform health care policy, Arbor Research contributes to the development and implementation of the **Prospective Payment System (PPS) for Federally Qualified Health Centers (FQHC)**. Under contract with the Centers for Medicare & Medicaid Services (CMS), the Arbor Research study team published a report in 2013 that describes analyses that informed CMS in their development of the proposed design of the FQHC payment system. Design features highlighted in the report include the unit of payment (i.e., per visit versus per unit of time) and payment adjustments. This report also describes relative advantages

and disadvantages of several policy options that CMS considered for the proposed FQHC PPS.

Continuing a long history of support for policy development, CMS awarded Arbor Research a 5-year competitive renewal of the **Measure and Instrument Development and Support (MIDS)** umbrella contract in 2013. Arbor Research is one of only 18 organizations throughout the United States that have received this designation. This contract allows us to bid on research projects to develop and implement measures of quality of care for CMS programs, including our current work providing support for the **ESRD Quality Incentive Program (QIP)** under this umbrella.

In addition to expert analysis, Arbor Research collects data and monitors the effects of health care policy changes. The **Dialysis Outcomes and Practice Patterns Study (DOPPS) Practice Monitor (DPM)** is a publicly-available tool that presents more than 800 regularly updated charts,

*Project Assistant Alex Turner, Managing Senior Analyst Alissa Kapke, and Research Analyst Yan Jin.*



figures, and data tables in an easily-accessible online format at [DOPPS.org/DPM](http://DOPPS.org/DPM). The DPM was designed and implemented to measure changes in hemodialysis care following the introduction of the U.S. bundled payment system for hemodialysis in January 2011. Since that time, the DPM has shown substantial changes in prescriptions and practices affecting hemodialysis patients. The DPM study team takes extra measures to share these data and analyses of trends in care with the nephrology community. The DPM is updated with fresh data every 2 months.

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## Our incisive data analyses inform policy makers.

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Public Web conferences are held three times a year to present findings and answer questions from other researchers and clinicians. In 2013, the team presented abstracts and symposia on DPM findings at the American Society of Nephrology's Kidney Week and the European Renal Association-European Dialysis and Transplant Association Congress. ■



*Arbor Research President Bob Merion.*



PLANNING FOR  
**smart growth**  
OUR CULTURE OF EXCELLENCE



This year, the Arbor Research staff undertook an organization-wide effort to create a 5-year strategic plan to guide our growth. The process of planning for our future included every member of the staff, and culminated in a clear and measurable plan that was approved by our Board of Directors in November 2013.

We are now in our first year of implementing our strategic plan. In doing so, we have committed ourselves to maintaining our culture of excellence by providing a challenging, stimulating, and supportive environment to support the talented people who work here. Our plan calls for attracting a diverse, interdisciplinary team, that is passionate about producing research that is focused on reducing the health and economic burden of chronic diseases and improving the delivery of health care.

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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.

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We believe that the achievement of these goals will result in 10% annual growth in personnel and revenue. Our capabilities and partnerships will take us into new clinical and policy areas, including research that embraces patients as stakeholders. ■

## OUR PLAN: AT A GLANCE

*What will be our focus for growth as an organization?*

Maintain the  
**CULTURE OF  
EXCELLENCE AND  
TEAMWORK**

Build capability within  
**NEW PRIORITY  
CLINICAL AND  
POLICY AREAS**

Establish relationships with  
**NEW EXTERNAL  
COLLABORATORS**

Attract a larger and  
more integrated  
**INTERDISCIPLINARY  
TEAM**

Expand and scale  
**CORE ANALYTICAL AND  
DATA MANAGEMENT  
CAPABILITIES**

Create a  
**RESEARCH ENVIRONMENT  
THAT EMBRACES PATIENTS  
AS KEY STAKEHOLDERS**

# 19

Private Funders

+

# 6

Government Agencies

support

# 93

Staff Members

to conduct  
research in

# 21

Countries

## Statement of Activities

	2013	2012
<b>REVENUES</b>		
Grants and contracts	15,328,129	15,760,351
Donations	419	4,281
Net investment earnings (loss)	2,285,736	1,296,682
Other income	3,822	5,782
Loss on disposal of property & equipment	-	(855)
<b>Total revenues</b>	<b>17,618,106</b>	<b>17,066,241</b>
<b>EXPENSES</b>		
Program services	13,685,409	13,628,619
Supporting services	2,687,133	2,117,939
<b>Total expenses</b>	<b>16,372,542</b>	<b>15,746,558</b>
<b>Change in net assets</b>	<b>1,245,564</b>	<b>1,319,683</b>
<b>Net assets, beginning of year</b>	<b>12,607,499</b>	<b>11,287,816</b>
<b>Net assets, end of year</b>	<b>13,853,063</b>	<b>12,607,499</b>

Arbor Research Collaborative for Health's total revenue during 2013 was \$17.6M, including \$15.3M in grants and contracts from 25 different private funders and government agencies. Investment returns further support our mission, and are derived from a healthy net asset balance of \$13.9M at close of 2013. The organization's activities, measured by yearly expenses of \$16.4M, have grown by 10% annually over the last two years. Our program efficiency—measuring the proportion of funds used directly for programs and services—was a highly competitive 84%, with only 16% of expenses in supporting services. We have 152 days in cash reserve, compared to the industry average of 133 days.



## Statement of Financial Position

	12/31/13	12/31/12
<b>ASSETS</b>		
Cash and cash equivalents	3,845,138	7,309,158
Certificates of deposit & investments	17,722,266	10,697,245
Grants and contract receivables	1,533,439	5,732,807
Prepaid expenses and other assets	398,972	240,924
Property & equipment, net	1,144,164	879,929
<b>Total assets</b>	<b>24,643,979</b>	<b>24,860,063</b>
<b>LIABILITIES</b>		
Accounts payable & accrued expenses	2,496,509	2,575,044
Deferred revenue	8,294,407	9,677,520
<b>Total liabilities</b>	<b>10,790,916</b>	<b>12,252,564</b>
<b>NET ASSETS</b>		
Unrestricted	13,842,613	12,597,468
Temporarily restricted	10,450	10,031
<b>Total net assets</b>	<b>13,853,063</b>	<b>12,607,499</b>
<b>Total liabilities and net assets</b>	<b>24,643,979</b>	<b>24,860,063</b>



## A STRENGTHENED COMMITMENT TO GIVING BACK

We've strengthened our commitment to giving back. In 2010, Arbor Research established a charitable giving program to reflect both the mission of the organization and the community interests of our staff. To support the demonstrated giving priorities of our staff, Arbor Research matches contributions from employees to eligible charities. In addition to matching employee contributions, we gave directly to 29 organizations in 2013 in three charitable giving areas that reflect our community: local/regional, medical/health care, and research. Our staff also participated in one "goods" drive per quarter which included the Humane Society of Huron Valley, Ronald McDonald House, a Red Cross blood drive, and a SafeHouse Holiday Drive. Finally, many on our staff had a great time supporting a building project with Habitat for Humanity, with additional underwriting from Arbor Research. ■

### COMPONENTS OF OUR CHARITABLE GIVING PROGRAM

- Employee giving match program
- Organizationally-directed giving
- Disaster relief
- Goods drives

*Research Analyst Sarah Forney and Senior Project Assistant Jenya Abramovich volunteer at the Habitat for Humanity site in Ypsilanti, MI, October 12, 2013.*



**"It's truly a pleasure to work for an organization that is committed to giving back so generously to both the community and other organizations that their employees feel passionate about."**

Anna Hogan, Senior Project Assistant and Chair of the Charitable Giving Committee

## ARBOR RESEARCH COLLABORATIVE FOR HEALTH

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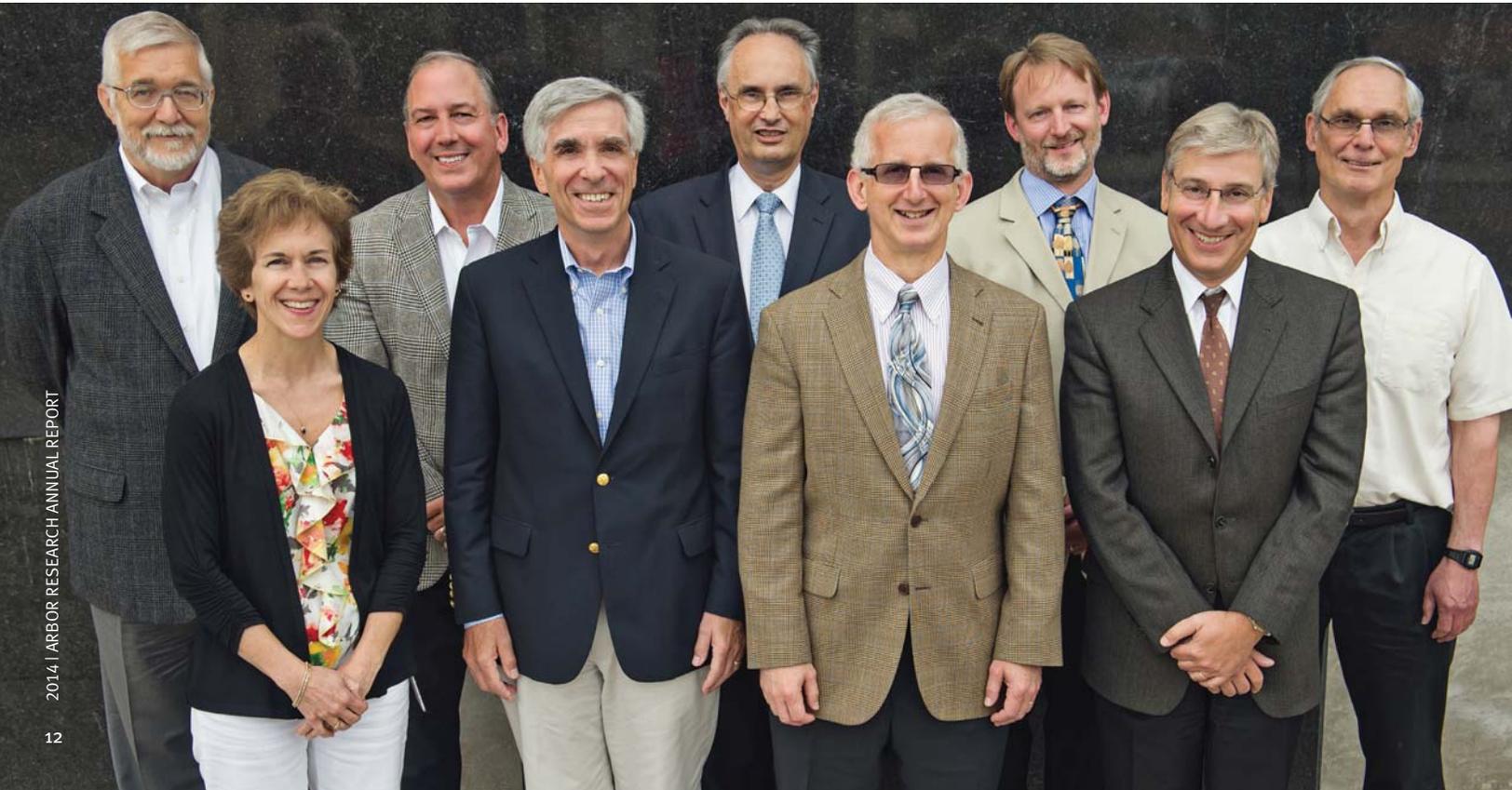
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### SENIOR MANAGEMENT

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