



WCG Foundation 2017 Annual Report

Improving Lives

by Delivering on the Promise of Research

Dear Friends,

Last May, WCG Foundation (WCGF) received an unexpected call for help. It came from Ann Fowler, who'd spent nearly two years trying to get approval for her husband, Tyson, to undergo an investigational treatment for crippling Lyme disease. As the process dragged on, Tyson grew weaker and weaker. By the time Ann called WCGF, Tyson was bedridden and on a ventilator.

That May day, Ann went online, typed in the words "independent IRBs" and "compassionate use," and our website came up. Within 10 days of WCGF's involvement, an institutional review board (IRB) had reviewed and approved the Fowlers' request. Food and Drug Administration authorization followed, and Tyson is now receiving treatment and showing improvement.

Their story is just one example of how support for our Expanded Access Project—and our other priorities—can change lives.

With donor support, in 2017 we helped more physicians get access to investigational medicines for their patients. We fine-tuned our education grant program so professionals from resource-poor countries can receive training in research ethics, and we introduced new grants to encourage university faculty and young scholars in the U.S. to strengthen their understanding of research ethics and protections for research participants. In addition, we laid the groundwork for our newest priority: increasing participation by populations that historically have been underrepresented in research.

All of these accomplishments were joint efforts. WCGF is privileged to have exceptional partners—corporations, foundations, and individuals who share our goals of advancing ethical research and helping more people realize its benefits. We also are fortunate to have a talented, dedicated Board of Directors. Each Board member brings an invaluable perspective, essential expertise, and an unwavering commitment to WCGF's mission.

WCGF ended 2017 encouraged by our successes, enthusiastic about the Foundation's future, and grateful to all who make our work possible. Their support and generosity truly are making a difference for countless individuals whose lives are better because of research.

With appreciation,

A handwritten signature in black ink that reads "Marjorie A. Speers". The signature is written in a cursive, flowing style.

Marjorie A. Speers, Ph.D.
Executive Director

A Report to Our Community

2017 was another building year for WCG Foundation (WCGF). We forged new partnerships, expanded our services, and broadened our focus—all in service of our goal of improving lives by delivering on the promise of research.

Since WCGF's founding, our emphasis has been on two priorities: helping desperately ill patients get access to investigational medicines and improving education in research ethics and compliance. In 2017, we added a third priority to address equity in research participation. We believe everyone should have the same opportunity to benefit from the knowledge and scientific advances that research makes possible, and we're working to increase opportunities for people to participate in research regardless of race, ethnicity, nationality, age, or gender.

With support from our donors, we have taken significant steps to advance all three of these priorities. Equally important, we are positioned for continued progress in the years to come.

Compassion through expanded access

WCGF's most significant progress last year was in the area of expanded access/compassionate use. The issue received considerable media coverage, in part due to increased federal support for proposed "right to try" legislation. WCGF seized the opportunity to voice support for the Food and Drug Administration's (FDA's) expanded access program, which makes investigational drugs available to patients who have exhausted all



other treatment and clinical trial options. We also supported FDA's recent, successful efforts to streamline the expanded access process.

WCGF leadership served on expert panels and collaborated with FDA and the Reagan-Udall Foundation for the FDA to help physicians, patients, and IRBs with expanded access. With support from GlaxoSmithKline, Johnson & Johnson, and Robert Wood Johnson Foundation, we stepped up our own expanded access education efforts by hosting our first free webinar for IRBs and physicians. Webinar materials remain available online, free of charge, along with other educational documents for IRBs and physicians.

We reached out to pharmaceutical companies and physicians, seeking their input on ways to improve the expanded access process. In addition, a grant from Pfizer enabled us to develop a needs assessment tool. Our next steps will be to use that tool to survey

physicians on what type of training they desire and how best to deliver it. We will use assessment results to set policies that could streamline the expanded access process and enhance physician compliance.

Inclusion for underrepresented populations

Some of our most exciting work in 2017 focused on finding new ways to engage populations that are underrepresented in clinical research. Studies suggest that groups that don't have access to—or don't participate in—clinical trials tend to receive poorer healthcare. That, in turn, has a negative effect on health outcomes.



WCGF has developed an innovative program that seeks to increase minority participation in research by reaching out to patients through existing primary care practices. Our goal is to pilot the program in Georgia,

where 31.7 percent of the population is African-American and 9.4 percent is Latino.



Education for research professionals

WCGF works with partners in industry, government, and patient groups to identify and address gaps in research ethics and education. In 2017, we made changes to increase the impact of our education efforts for researchers in the U.S. and research professionals from resource-poor countries.

Our new salary grants help U.S. faculty further their understanding of research ethics and protections for research participants. New grants to support master's theses and doctoral dissertations encourage young U.S. scholars to conduct research on research ethics, protections for research participants, and regulatory

compliance. Revisions to our education grant program create new opportunities for international research professionals to benefit from research ethics training in the U.S.

Our two-year grant to New York University Langone Medical Center (NYULMC) ended in mid-2017. Last year's efforts focused on continued curriculum development and outreach via lectures, webinars, and panel discussions. During the grant period, hundreds of physicians, residents, and medical students at NYULMC participated in rounds presentations on research ethics. Furthermore, research professionals around the globe attended presentations on ethical considerations involved in expanded access.

2018 and beyond

Looking ahead, WCGF will continue to strengthen existing program offerings and seize opportunities to address gaps in expanded access, inclusion, and research ethics education. We will seek out additional partners and play a more visible role as a go-to resource on issues related to our core priorities.

Already, in 2018, we have extended our expanded access resources to include information on the processes for both single patient and intermediate-size patient populations. We also have increased public engagement through social media and other proactive communications efforts.

WCGF expects to launch our inclusion project for underrepresented populations in the coming year and, ultimately, to extend the initiative to additional communities nationwide. We also plan to award more education grants to international research professionals and encourage continued research ethics education in the U.S. In every endeavor, we will remain true to our vision of serving society by delivering on the promise of research.



WCGF 2016 & 2017 Statement of Financial Position & 2017 Donors

ASSETS

CURRENT ASSETS

	2017	2016
Cash	\$ 317,056	\$ 186,240
Grants receivable	\$ 10,000	\$ 50,000
Contributions receivable	\$ 1,000	\$ 4,000
Prepaid expense	\$ 4,181	\$ 3,865
Total current assets	\$ 332,237	\$ 244,105

OTHER ASSETS

	2017	2016
Website design costs	\$ 14,500	\$ 14,500
Less accumulated amortization	\$ 9,667	\$ 4,833
Total other assets	\$ 4,833	\$ 9,667
Total other assets	\$ 337,070	\$ 253,772

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES

	2017	2016
Accounts payable and accrued expenses	\$ 2,027	\$ 5,496

NET ASSETS

	2017	2016
Unrestricted	\$ 335,043	\$ 209,643
Temporarily restricted	--	\$ 38,633
Total net assets	\$ 335,043	\$ 248,276
Total liabilities & net assets	\$ 337,070	\$ 253,772

2017 DONORS

Corporations

Johnson & Johnson
Pfizer
WIRB-Copernicus Group

Individuals

\$5,000 and up
Drs. Daniel Blumenthal and Marjorie Speers
Mr. and Mrs. Stephen McLean

\$2,500-\$4,999

Mr. Alan Lefkowitz

\$1,000-\$2,499

Academy of Physicians in Clinical Research
Dr. Anita Allen
American Journal of Managed Care
Mr. David Farber
Dr. Angelike Giallourakis
Kenneth and Joelle Marquis Charitable Fund
Dr. Joanne Waldstreicher

\$500-\$999

Dr. Peter Buckley
Getz Family Charitable Giving Fund
Clifford and Sandra Jackson
Dr. Lindsay McNair

\$1-\$499

James and Linda Ginzer Charitable Fund
Dr. Robert Hood
Mr. Mark Marchand and Ms. Elisa Gallaro
Ms. Suzanne Nixon