



AN UNLIKELY PARTNER FOR HEART PATIENTS

The Department of Defense Peer Reviewed Medical Research Program welcomes input from heart patients and families. By Heather R. Johnson

DONNETTE SMITH, PRESIDENT OF Mended Hearts and Chairman of the Board of Directors, has served in numerous national-level roles and participated in multiple national media campaigns. But for all of the time spent spreading the word about heart health, she hadn't had the opportunity to make a difference in medical research.

That changed a few years ago when the Department of Defense reached out to Mended Hearts to recruit volunteers for its Congressionally Directed Medical Research Programs (CDMRP). Through CDMRP's Peer Reviewed Medical Research Program (PRMRP), Mended Hearts members can advocate at the biomedical research level.

Launched in 1992, the CDMRP funds high-impact, high-risk projects that other agencies won't touch, filling in gaps in traditional medical and scientific research. With the PRMRP, created in 1999, consumers — patients, survivors, family members and advocates — sit alongside scientists and clinicians to review potentially groundbreaking projects that need funding. Consumer input helps ensure that researchers consider the patient and family perspective in their work.

Offering a Patient's Perspective in Medical Research

Patricia C. Modrow, Ph.D., Program Manager for the Department of Defense PRMRP, states that consumers use their own experiences, as well as those of the community, to offer "fresh perspectives and insights" that other panel members may not have.

The scientist may not have a child with CHD. The researcher probably hasn't suffered a major heart attack. By sharing their opinions based on these experiences, consumers help researchers find new ways to develop projects to provide even

WHAT MAKES A GOOD PEER REVIEWER CANDIDATE? HERE IS CDMRP'S SHORT LIST.

- Be willing to share your personal story.
- See beyond that story to the stories of fellow heart patients to represent the entire community.
- Have knowledge about the full spectrum of family and patient heart concerns.
- Have the confidence to express opinions that may differ from scientific reviewers.

For a full eligibility checklist, visit <http://cdmrp.army.mil/cwg>.

better treatments.

When Mended Hearts nominated Smith to participate in the program in 2014, she immediately said yes. "I've learned so much it's mind-boggling," she says. "Whether it's a device or a drug that they discuss, it's incredible to see what's out there. We get to review them and grade the merit. To be in that conversation with doctors and scientists is quite an honor." She's participated every year since.

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Although you don't have to have a medical background to participate, you do have to be willing to spend time in a peer review meeting and in pre-meeting preparation. It typically takes about 40 hours over a four- to six-week period to complete pre-meeting preparation. During this time, participants receive training, review applications, and write comments in those applications. Smith says her groups generally review 25 to 30 applications. The panel grades each grant



"I've learned so much it's mind-boggling," says Donnette Smith of her participation in the Department of Defense's Peer Reviewed Medical Research Program, which allows consumers to weigh in on groundbreaking medical projects that need funding.



"I love the idea of being part of research and new treatments in the beginning stages," says Andrea Baer, who also participates in the Peer Reviewed Medical Research Program.

request and the projects are rated accordingly. The panelists discuss the scoring during the peer review meeting.

The peer review meeting either meets over one to three afternoons via video-conference or teleconference, or in person over two to three days in Washington, D.C. (The program does pay travel expenses.) "Two days in a room with a computer and a bunch of people!" Smith laughs. "But you learn so much."

Funding for Heart-Related Research Projects

PRMRP covers a wide range of conditions, from alcoholism to PTSD to eye injuries. During fiscal years 2015 and 2016, the program funded women's heart disease projects. Congenital heart disease (CHD) has been a topic area for the past three fiscal years. Other heart-related topic areas include cardiovascular health and diabetes.

Modrow states that Congress recognizes CHD as "an issue of importance" to military families. It supports CHD research that will benefit not just service member families, but all families. She also states that, as directed by Congress, PRMRP will continue to support research to promote heart health.

In fiscal year 2014, PRMRP awarded grants supporting five CHD research projects. Nikolay Vasilyev, M.D., of Boston Children's Hospital, proposed to design and build an implantable intracardiac device that, according to a CDMRP news article, "will support circulation with a dynamic pulsatile force timed to the heart contraction." The device will require less anti-coagulation treatment and will use a patient's own ventricular chamber as the pump.

Thomas Barker, Ph.D., of Georgia Tech Research Corporation, is part of a team that developed synthetic platelet-like particles (PLPs) that share

many features with natural platelets. He plans to demonstrate that the PLPs can decrease bleeding problems associated with cardiopulmonary bypass.

Mended Hearts Makes an Impact

Mended *Little* Hearts nominated Andrea Baer, Director of Patient Advocacy for Mended Hearts and Mended *Little* Hearts, to serve as a consumer peer reviewer in 2014. She also served in 2015 and is on the docket for 2016.

"I thought that it was a great opportunity to really be the voice of the patient," she says of her reason to volunteer. "I love the idea of being part of research and new treatments in the beginning stages. The peer review program gives the consumer a voice in the process."

For Baer, serving as a peer reviewer gives her one more way to make a difference in the lives of children affected by CHD. As a mother of four, including Trenton, who had open-heart surgery to repair a defect at 11 weeks old, Baer recognizes the impact the program can have on heart patients. "Having the ability to give input on what I felt the community could use in terms of research is really important," she says.

Smith brought decades of personal experience to her peer reviewer role. Born with a bicuspid aortic valve and aortic stenosis, Smith has had five open-heart surgeries and has five stents. "Anything related to the heart or the medical field interests me of course," she says, noting that heart disease runs deep in her family. "In these meetings, you can get your point across as a patient or a mother or a caregiver. We can make a difference at the level of getting projects funded."

Smith stresses that caregivers and heart patients should consider getting involved in initiatives such as the PRMRP. "That's when we have a real voice." ❤️

Photo of Andrea Baer courtesy of Mended Hearts; Photo of Donnette Smith courtesy of Jeffrey J. Hanshaw