



Consumer Involvement

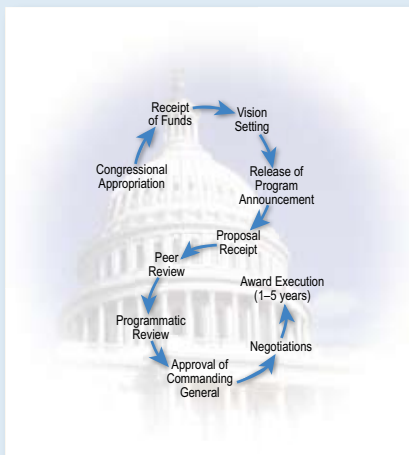
Expanding Our Tradition



Congressionally Directed Medical Research Programs

History

In 1992 the Congressionally Directed Medical Research Programs (CDMRP) was born from a powerful grassroots effort led by the breast cancer advocacy community that convinced Congress to appropriate funds for breast cancer research. This enabled a unique partnership among the public, Congress, and the military. Funds for the CDMRP are added annually by Congress to the Department of Defense budget to provide support for targeted research programs focused on a variety of cancers, genetic diseases, trauma-induced medical issues, childhood diseases, and other areas of health interest to military personnel and their families, the veteran population, and the general public.



Two-Tier Proposal Review Process

The CDMRP program management cycle follows a two-tier review model recommended by the National Academy of Sciences Institute of Medicine. Each level of review involves dynamic interactions between scientists, clinicians, and consumer advocates. The first tier is a peer review of proposals against established criteria for determining scientific and technical merit. The second tier is a programmatic review, conducted by the Integration Panel, which compares proposals against each other and makes funding recommendations based on published programmatic review criteria such as peer review ratings, program portfolio composition, and overall program goals. This two-tier model and the inclusion of consumers have received high praise from the scientific community, advocacy groups, and Congress.

“Consumers remind all scientists of the human component of disease.”

—Institute of Medicine

A consumer is a patient, survivor, family member, or caregiver of a person living with a disease, injury, or condition. Consumers work collaboratively with leading scientists, clinicians, and members of the military in establishing program priorities, participating in the scientific peer review of research proposals, and developing funding recommendations. They contribute unique perspectives gained through their personal experiences, bring a sense of urgency to all levels of decision making, and serve as liaisons between their constituencies and the scientific community to increase awareness about their disease, condition, or injury.

CDMRP Vision:

Find and fund the best research to eradicate diseases and support the warfighter for the benefit of the American public.

CDMRP Mission:

We provide hope by promoting innovative research, recognizing untapped opportunities, creating partnerships, and guarding the public trust.



“For an addict to come from the depths of this disease to working side by side with scientists and professionals who have a commitment in helping with the prevention and recovery of alcohol and drug addiction makes me realize that we are not alone.”

—Jeannie Villareal, Consumer Reviewer,
Peer Reviewed Medical Research Program



“To contribute reason and practical knowledge in tandem with the greater scientific community presents a unique opportunity to improve care and influence guidelines and policy. This in turn creates paths leading to greater independence and self-reliance—paths created by the inroads that I and others have had to traverse.”

—Charles Gatlin, Captain, U.S. Army (Retired), Consumer Reviewer
Psychological Health/Traumatic Brain Injury Research Program

Interested in participating as a consumer peer reviewer?

CDMRP consumer requirement checklist:

- ✓ Be a person with the disease, condition, or injury or be a family member or caregiver of a person living with a disease/injury/condition associated with a funded program. Specific requirements vary by program. To find out more, please go to http://cdmrp.army.mil/cwg/program_requirements
- ✓ Be an active participant in an advocacy, outreach, or support organization in your local or national community and be nominated by your organization
- ✓ If you are military personnel on active-duty, be approved by your immediate supervisor
- ✓ Have at least a high school diploma or its equivalent
- ✓ Be fluent in reading, speaking, and writing English
- ✓ Have an interest in expanding your personal scientific knowledge about the disease, condition, or injury
- ✓ Represent the views of the consumer community, not only a personal perspective
- ✓ Have basic computer skills and have access to a computer with an Internet connection

“I have an enormous amount of respect for the scientists, so when they thank me for my involvement in the review process I am taken aback! Here I am in awe of them and what they do, and the fact that they respect and listen to the consumer perspective floors me. But it is also what makes the program so special. Consumers are giving something to the scientific community by offering glimpses of their life. A lab rat could never do that.”

—Fiona Hoey, Consumer Reviewer, Multiple Sclerosis Research Program





Consumer Involvement for Peer Review: Step by Step



“I enjoyed the peer review panels. I was able to network with other advocates fighting for lung cancer research. In addition, I really enjoyed sitting next to scientists and oncologists who are fighting the disease.”

**Montessa Lee, Consumer Reviewer,
Lung Cancer Research Program**



“I [was] very impressed by the quality of the proposals as well as the efficient and fair review process. The scientific community has many innovative and exciting ideas on the underlying causes of bone marrow failure, better ways to diagnose bone marrow failure, and better treatment options.”

**Cheryl Heisey, Consumer Reviewer,
Bone Marrow Failure Research Program**



Step 1 Preparation

- Identify relevant programs
- Explore programs by visiting <http://cdmrp.army.mil/cwg/default>
- Review eligibility requirements
- Obtain the Consumer Nomination Form

Step 2 Nomination

- Complete nomination form
- Obtain recommendation (nomination) letter
- Submit completed packet, nomination letter, resume, and personal statement

Step 3 Screening and Selection

- Nomination Package is evaluated for advocacy (for non-military personnel), interest in science, communication skills, and participatory skills
- Informal telephone interview is scheduled
- Selection and notification occur

Step 4 Panel Placement

- Receive peer review panel assignment
- Participate in training and review educational materials
- Get acquainted with other consumer reviewers



“I understood firsthand that there was an enormous community of noble-minded individuals trying to save lives and take care of patients and families of which I needed to be a part. How could I be the beneficiary of such kindness and good will without contributing to that same community myself?”

**John F. Kennedy, Consumer Reviewer,
Peer Reviewed Cancer Research Program**



“I would like to share the following with prospective consumer reviewers: Come in with a very open mind. Be prepared to read, read, and read some more. Your opinion is more important than you think. When I returned home, I was so empowered about decisions that I made because I knew they were the right decisions.”

**Debra Vines, Consumer Reviewer,
Autism Research Program**



“During my chemotherapy regimen 9 years ago, I remember telling my husband, 'Some day I will go to Washington to advocate for the eradication of breast cancer.' It has been thrilling to serve as a reviewer and to imagine the impact that the medical research could have on all of the breast cancer patients I have met as a peer counselor and advocate.”

**Amalia Rigoni, Consumer Reviewer,
Breast Cancer Research Program**

Step 5 Review Applications

- Read application components
- Write preliminary critiques
- Provide preliminary scores

Step 6 Participate in Peer Review Panel Discussions

(online, teleconference,
or in person)

- Attend orientations
- Contribute to panel discussions
- Revise critiques
- Listen and learn

Step 7 Finishing Up

- Provide feedback and suggestions for improvement
- Fill out online surveys



Step 8 Spread the Word

- Place a press release
- Report back to organization via meetings, web sites, blogs
- Inform others about opportunities to serve as a consumer reviewer



“From this experience I have learned to ask much smarter questions on behalf of the TS Community and on behalf of [my son] Bao. I have also learned that this is the single most important thing I can do for my son and for all those suffering from TSC.”

**Ron Heffron, Consumer
Reviewer, Tuberous Sclerosis
Complex Research Program**



“I work locally to bring ovarian cancer awareness to others. We raise money for research, but getting involved in the CDMRP gave me a chance to work nationally and globally to do something for other women.”

**Lisa Sienkiewicz, Consumer Reviewer,
Ovarian Cancer Research Program**



CDMRP consumer reviewers: 1,600 strong

“When my daughter Molly was born, I had never heard of the word 'Neurofibromatosis' (NF), yet today, I am all too familiar with NF and all of its manifestations. When Molly was just 8 months old, she was diagnosed with a plexiform neurofibroma. This tumor had grown to press against her esophagus and was beginning to cut off her air supply. Years later, one day out of the blue Molly said, 'Mom, you know we have two families.' Confused I asked, 'What do you mean?' She said, 'Well, we have our family and we have our NF family.' As one big family and from the bottom of my heart, I am eternally grateful for the efforts made by such programs like the CDMRP! I have made it my life-long goal to teach others about NF. There are countless ways how our family has and continues to help each other out. Together, we WILL soon see a cure for NF.”



Susan Johnson with 10-year old daughter Molly

—Susan Johnson, Consumer Reviewer, Neurofibromatosis Research Program

“I learned about prostate cancer and the health disparities associated with it as a consequence of my own diagnosis, and it has been my distinct honor and privilege to serve with the expert scientists and clinicians. Currently, I speak at community events as much as I can, in an effort to help others in the struggle. After speaking at a church engagement, a lady mentioned that her brother was diagnosed with prostate cancer, and I subsequently formed a relationship with him, giving him information and discussing treatment options. Amazingly, while he was in post op, his wife called to tell me that he was doing fine and she personally thanked me for saving her husband's life. Moments like these strengthen my determination to work inside and outside CDMRP, educating others and helping to chart the research course for finding a cure.”



Colonel Artie Shelton (L) and Onias Dickson Jr. (R) working together to educate others about prostate cancer at a health fair

—Artie Shelton, M.D., Colonel, U.S. Army (Retired), Consumer Reviewer, Prostate Cancer Research Program



Sandy Chapman paddles out to the center of a lake for the “One Square Mile of Hope” event

“I view my diagnosis as a gift. It has strengthened my faith, my family relationships, and my personal friendships. It has taught me what is important in life and it has brought to me a new world of consumer advocacy for breast cancer research. Fifteen months after my diagnosis I participated in a Susan G. Komen race for the cure event titled 'One Square Mile of Hope.' A group of individuals came together on a lake in the Adirondacks to paddle out to a point on the lake to gather in support for the cure of breast cancer. We not only came together, we set a new world record! Our record of 1,104 canoes/kayaks raft to free float in a body of water beat out the existing record of 776 set in 2001. This is what I see here with this group [CDMRP], individuals coming together to create a critical mass of knowledge and understanding for the cure of breast cancer and participating in a process that will help identify noteworthy research proposals for funding. It is an honor to be part of this group.”

—Sandy Chapman, Consumer Reviewer, Breast Cancer Research Program

**To read more uplifting stories written by consumers, please visit
<http://cdmrp.army.mil/cwg/stories>**



Lieutenant Ian Brown at the top of a mountain during a hike through the mountains of Alaska

“In 2002, while serving as a pilot in the United States Air Force, I became paralyzed in the line of duty. Striving to improve my life however I can, I have focused on studies related to my personal injury, any and all research applicable to my situation, recent discoveries, promising technologies, and new research, while exercising my body in hopes of a speedy rehabilitation in the event of a cure. Simultaneously, I am exercising my mind by applying to medical school. Some of my volunteer activities include helping newly injured patients transition to their new lives, and volunteering for 'Lasher Sport,' where I help to fit customized wheelchairs to people with disabilities. Working as a consumer reviewer for CDMRP allowed me to take an active role in my own spinal cord injury awareness and advocacy. Most importantly, I have learned how critical it is to help the medical community understand the issues most pertinent to those [of us] living with spinal cord injuries so they may better tailor the direction of research.”

—Ian Brown, Lieutenant, U.S. Air Force (Retired), Consumer Reviewer, Spinal Cord Injury Research Program

“When I was first injured in 2005, I definitely saw the world differently. While doing a rapid dismount, I fell from a truck while serving for Operation Iraqi Freedom and severely injured my back. I have endured two back surgeries with the end result being a paralyzed nerve. When I heard about the CDMRP, I felt that this was my way to give back. I could actually use my experience in dealing with pain, frustration, medication regimens, et cetera to help others to have an even better experience than I did. Working with the CDMRP has shown me that I may not be of service to the U.S. Army nor my few soldiers in combat anymore, but I can still serve them. Just in a different capacity. For anyone who has a heart to help others, has an experience to share that aligns with the needs of the CDMRP, and can dedicate the time and energy that are required to view proposals and fairly critique them, this may be a great opportunity for you.”



Private First Class Zaneta Adams

—Zaneta Adams, Private First Class, U.S. Army (Retired), Consumer Reviewer, Peer Reviewed Orthopaedic Research Program



Captain David Winnett

“I am not a wealthy man. I'm not even a healthy man anymore; at least not physically. But the spiritual wealth I have acquired through the experience of chronic illness and pain make me one of the richest men in this country. Pain and suffering have made a better man of me. It has awakened a part of my spirit that I never knew existed. It has awakened my sense of compassion and empathy for those who suffer alongside me, but who are not blessed with the ability to continue working and providing for their families as I am. God supplied me with the sound mind and body required to be a successful Marine. It's now clear to me that my destiny all along was to become a front-line warrior in the fight to uncover the mysteries surrounding Gulf War Illnesses. The Gulf War Illness Research Program is a vital link in the chain of events that will eventually bring relief to tens of thousands of American heroes.”

—David K. Winnett Jr., Captain, U.S. Marine Corps (Retired), Consumer Reviewer, Gulf War Illness Research Program



Cover (top): L, Susan Senator, Autism Research Program; R, John F. Kennedy and family, Peer Reviewed Cancer Research Program

Front cover (bottom): L to R, CeCe Whitewolf, Breast Cancer Research Program; Paul Perrone, Multiple Sclerosis Research Program; Fredda Bryan, Breast Cancer Research Program; Scott Mitchell, Peer Reviewed Medical Research Program; Noah Fenn, Genetic Studies of Food Allergies Research Program

Header photos: Jocelyn Whitfield Banks, Breast Cancer Research Program (page 2); Steve Senderoff, Amyotrophic Lateral Sclerosis Research Program (page 4); Sarah Keitt, Multiple Sclerosis Research Program (page 6)

Back cover: Bao Heffron and his mother Ann Heffron, Tuberous Sclerosis Complex Research Program

For information, visit

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