

The STEP Program™: Supporting Solutions from Patient Advocacy Organizations ^[1]

Education & Awareness ^[2]

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The STEP Program™: Supporting Solutions From Patient Advocacy Organizations

Patient advocacy organizations are a key source of information, empowerment, and support for patients at every step of their health care experience, helping them and their families navigate the care they need.

Novartis developed the STEP (Solutions to Empower Patients) Program™ to fund innovative projects from United States (US)–based nonprofit organizations that help address some of the most pressing gaps between best practices and the care a patient — or caregiver — actually receives. By supporting the patient advocacy organizations that are best positioned to tackle these unmet needs, our goal is to reduce the burden of disease and help create a path to better care.

Proposal Submission And Review Process

Every year the STEP Program addresses a specific disease, condition or aspect of health care in which advocacy organizations are invited to submit proposals to develop programs or resources that address that one area of significant unmet need. Once the submission period closes, an external review committee evaluates the proposals against common criteria and identifies those with the greatest potential to make a positive impact on patients and caregivers.

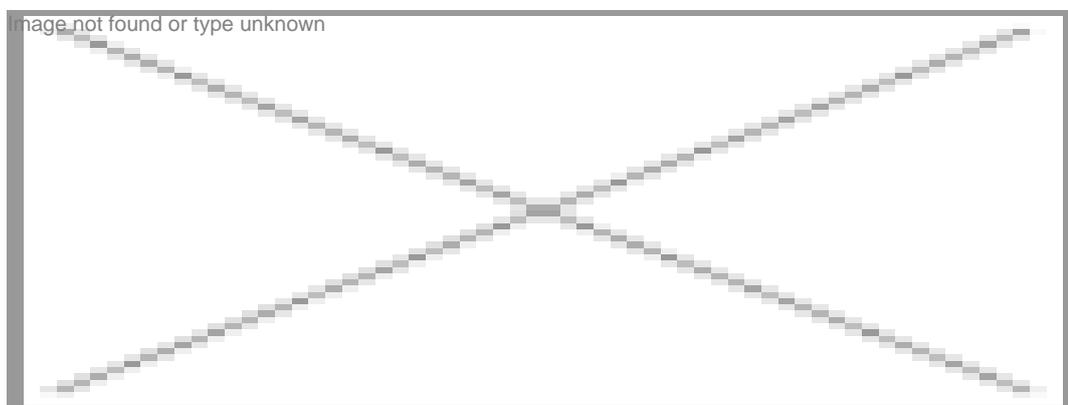
Each review committee consists of a diverse group of subject matter experts, including health care providers and patients and/or caregivers, to provide broad perspectives on the submitted proposals. Once the final proposals are identified, recipients are notified and recognized by Novartis.

Current Focus Area: Raising Awareness Of MS Caregiver Needs

**Please note the review committee is in the process of identifying funding recipients of the STEP Program for MS caregivers. Applicants will be notified of the review committee's decision on or before May 29, 2020.*

Multiple Sclerosis, or MS, is a chronic, debilitating disease of the central nervous system that can significantly impact the lives of people living with the condition, as well as families and loved ones.^{1,2} Due to the unpredictable nature of the disease, caregivers (also called “support partners” or “care partners”) can face challenges on many fronts while navigating the often-changing care needs for their loved one living with MS.³ While there is some support available for caregivers, there is an opportunity to do more.

To help improve caregiver support, the STEP Program will recognize and fund up to two proposals that demonstrate innovation in the following areas:



For more information on this iteration of the STEP Program, please view the [MS caregiver submission FAQ](#) [3].

STEP Program Funding Recipients

Since its creation, the STEP Program has funded a variety of programs and resources that are helping to address educational gaps for patients, their caregivers, and the health care community.

Current Focus Area: Advancing Biomarker Testing In The Cancer Community

**Please note the review committee is in the process of identifying funding recipients of the STEP Program for biomarker testing. Applicants will be notified of the review committee's decision on or before January 31, 2020.*

With the acceleration of personalized medicine, we hope that treatments will one day be tailored to each person's cancer.⁴ In oncology, personalized medicine is often guided by results of biomarker testing that can identify specific changes in cancerous cells. This testing is also referred to as genomic testing, molecular profiling or tumor profiling, among other names.⁴ Though biomarker testing has become one of the cornerstones of personalized medicine, especially within oncology, there remain significant challenges when it comes to

education, access and reimbursement.⁵⁻⁷

To help improve testing rates, the STEP Program will recognize and fund proposals that demonstrate innovation in the following areas:

- Awareness and education
- Self-advocacy
- Policy improvement

For more information on this iteration of the STEP Program, please view the biomarker program submission [FAQ](#) ^[4] or read our press release.

Sickle Cell Disease (SCD) Recipients Represent Broad Impact Of The Disease

SCD is a genetic blood disorder that produces abnormal red blood cells which cause ongoing damage to blood vessels and organs.⁸ It is a lifelong illness that places physical and emotional burdens on patients and their families as they manage issues with work, school and family.

Through the STEP Program, five organizations received a total of nearly \$250,000 for their proposals to improve the lives of people living with the disease.



Funded programs include:

- All One Blood's video series ^[5]
 - Revealing powerful stories of those living with SCD to encourage self-advocacy.
- Children's Research Institute's INSERTT (ImproviNg SickIE TRansition Through Telemedicine) ^[6]
 - A study evaluating telemedicine on improving health outcomes for SCD patients as they transition to adult care.
- Sickle Cell 101's FACTSS (FAcilitating Communication BeTween PatientS and ProviderS) ^[7]
 - A digital toolkit with customized communication strategies to empower patients to take control of their care.
- The Georgia Health Policy Center at Georgia State University's educational videos ^[8]
 - Equip patients and caregivers about the benefits and potential complications of therapeutic blood transfusions.
- The Sickle Cell Foundation of Georgia, Inc.'s interactive workshops ^[9]
 - Providing adolescents with tools to successfully transition from pediatric to adult care.

Proposals were evaluated by an external review committee comprised of experts in the fields of advocacy, psychosocial support and multicultural health, as well as an SCD practitioner and patient.

Metastatic Breast Cancer (MBC) Recipients Making A Difference

Approximately 155,000 Americans are living with MBC, a form of cancer that has spread from the breast to other parts of the body such as the brain, bones or liver.^{9,10} At this stage, the disease is incurable and life expectancy drops dramatically.¹¹ An MBC diagnosis can be overwhelming, and people living with the disease face many unique challenges.

Through the STEP Program, three advocacy organizations were provided a total of \$225,000 to support the MBC community.



Funded programs include:

- FORCE's XRAY: MBC (eXamining the Relevance of Articles for You: Metastatic Breast Cancer) ^[10]
 - A resource that helps patients and their caregivers interpret media coverage of MBC research, understand the relevance of this research for their clinical care and discuss the information with their health care providers.
- METAvivor's MBC PREP (Metastatic Breast Cancer Patient Resource and Education Portal) ^[11]
 - Enables patients to easily access online information specific to their MBC diagnoses to make personalized and informed choices about their health.
- PAF's Financial Resource Directory for Metastatic Breast Cancer Patients ^[12]
 - An online tool that delivers information about financial resources to patients and caregivers who are experiencing or at risk of debt crisis as a result of their MBC diagnosis.

Proposals were evaluated by experts in psycho-oncology, nurse navigation, as well as an MBC caregiver and expert in advocacy.

Recent Press Releases

- Novartis STEP Program™ now accepting submissions for proposals that address unmet patient needs in cancer biomarker testing ^[13]
- Five nonprofit organizations to receive up to \$250,000 through Novartis STEP Program™ to support sickle cell patient initiatives

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- [Novartis to fund five innovative ideas to support patients and the sickle cell community](#) [14]
- [Novartis announces funding for patient advocacy initiatives to support and empower metastatic breast cancer community](#) [15]
- [Novartis launches STEP Program™ to inspire solutions for people living with metastatic breast cancer](#) [17]

Contact Us

For questions about the STEP Program, please contact a member of the STEP Program team at step.program@novartis.com [18].

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Links

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- [2] <https://www.novartis.us/stories/education-awareness>
- [3] https://www.novartis.us/sites/www.novartis.us/files/T-NOV-1384645%20STEP%20Program%20MS%20Caregivers%20Submission%20FAQ%20Q1%202020_0.pdf
- [4] https://www.novartis.us/sites/www.pharma.us.novartis.com/files/ONC-1218584%20Biomarker%20STEP%20Submission%20FAQ_10.4.19.pdf
- [5] <http://www.alloneblood.org/>
- [6] <https://childrensnational.org/research-and-education/about-cri>
- [7] <https://www.sc101.org/>
- [8] <https://ghpc.gsu.edu/>
- [9] <https://sicklecellga.org/>
- [10] https://www.facingourrisk.org/index.php?gclid=CjwKCAjw3azoBRAXEiwA-_64OrPC1ChbGHKHMffl_JGG_Hx4LzaVEpay3ipqRbc6FAu0DpTRdkVHzhoCF4IQAvD_BwE
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- [17] <https://www.multivu.com/players/English/8174651-novartis-launches-step-program/>
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- [20] https://www.caregiving.org/pdf/research/MSCaregivers2012_FINAL.pdf
- [21] <https://www.cancer.gov/about-cancer/treatment/types/precision-medicine>
- [22] <https://lungevity.org/sites/default/files/file-uploads/testing-terminology-world-lung-2016-poster.pdf>
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