



MyPCR.org

My PCR

2016 Executive Report

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Executive Summary:

The My PCR (myPCR.org) is an ongoing initiative designed to raise awareness among people living with chronic myeloid leukemia (CML), caregivers, advocates and physicians of the importance of regular, standardized CML diagnostics and monitoring. The campaign is directed and carried out in partnerships with 75 CML patient associations and 3 partner networks spanning over 60 countries in the regions of Latin America, Africa, the Middle East, Europe, North America and Asia. Since the campaign's inception in 2012, a core focus of the campaign has been to raise awareness through community driven efforts led by patient associations in their local communities.

In 2016, the My PCR campaign focused heavily on increasing direct engagement with My PCR partner organizations. Based on feedback received from partner organizations in 2015, we tailored our 2016 campaign towards creating initiatives that would directly support partners to develop advocacy strategies in their countries aimed at improving access to PCR testing. A core initiative of the 2016 campaign was the development of the My PCR Advocacy Toolkit.

In addition, we continued to offer grant opportunities to partners to engage with their physicians, host awareness events and attend hematology society conference. In 2016, My PCR offered the following three grant opportunities to partners: Hematology Society Grants, My PCR Event Grants and World CML Day "Treat Your Physician" Grants. Hematology Society Grants provided funding of up to US\$2,000 per grant for partner patient organizations to attend a hematology society conference in their home country and host a PCR campaign booth at the event. This provided patients with a platform with which to engage with industry leaders, physicians and fellow patients about country specific PCR related issues and needs.

The PCR Event Grants provided partner patient organizations with up to US\$1,000 to use towards hosting a PCR awareness event locally in their community. The World CML Day "Treat your Physician" grants were offered for a second year in a row by request from the partners who found the grants beneficial in 2015. This grant serves as a tool for providing partners with the opportunity to bring a My PCR themed edible treat, such as a cake or candy, to their physicians along with an informational World CML Day poster. The goal of this grant opportunity was to leverage World CML Day to engage patients with their physicians in a nonclinical way to discuss PCR and to build relationship.

The campaign was also represented at several international conferences and numerous regional conferences and patient/physician workshops around the world, continuing to deepen the exposure of patients, physicians and caregivers to the campaign, while continuing to represent the campaign as a professional community driven initiative with a strong presence within the global CML community.

In 2017, My PCR will focus on continuing to provide impactful resources and tools to CML patient advocates and partner organizations. A significant area of focus will be on providing partners with grant opportunities to utilize the My PCR Advocacy Toolkit to conduct advocacy initiatives in their local communities.

Thanks to the following campaign sponsors for their generous support: Ariad, Bristol-Myers Squibb, Novartis, Pfizer and Cepheid.

Background:



There is a significant need to increase awareness among patients and physicians of the importance of monitoring residual disease levels and understanding PCR test results. PCR stands for 'polymerase chain reaction' and is a diagnostic and monitoring tool used in CML to measure the response to treatment. It is generally one of the most sensitive ways to determine whether a patient has CML, and it is one of the most reliable tools for monitoring the presence of the disease in a patient once they

start receiving treatment. Because CML is a disease that usually requires lifelong treatment, regular monitoring for disease progression is critical to achieving positive outcomes for CML patients (every 3-6 months depending on patient's level of response to treatment).

The challenges are 1) PCR test requires diagnostic equipment that is not available in all countries 2) not all physicians are properly trained on the importance of PCR testing for CML patients 3) many CML patients do not understand what PCR testing is and why it is so critical to their health.

The My PCR aims to address these challenges. The campaign is a community driven - global awareness campaign aimed at increasing awareness among patients and physicians about the need for patients to access PCR to regularly monitor their treatment, leading to the optimization of clinical outcomes. It is carried out in partnership with a coalition of CML-focused organizations, with the goal of optimization of clinical outcomes for people living with CML.

The campaign features educational information such as FAQs about CML and PCR testing that are translated into over 25 languages, as well as patient tools such as the My PCR Wallet card, featuring key questions for CML patients to ask their physicians about PCR. Partner grants to support PCR awareness events, the dissemination of educational materials and advocate attendance at local hematology society conferences are also a key feature. My PCR, originally called the "What is MY PCR?" campaign, was launched on World CML Day, September 22, 2012, through a partnership among CML patient organizations and key opinion leaders on CML.

Campaign Goals:

- To increase patient awareness of the importance of monitoring the level of residual disease
- To increase patient understanding of the milestones in CML treatment
- To increase patients' involvement in their treatment
- To increase local community awareness of the needs of CML

2016 Campaign Initiatives:

1. My PCR Toolkit

In 2016, My PCR partners provided feedback that guidance around advocacy best practices was needed. While there are many resources available online for understanding effective advocacy strategies, My PCR partners noted that there are no advocacy toolkits that specifically related to PCR testing for the diagnosis and management of CML. In response to this, The Max Foundation initiated a co-creation process for developing a toolkit, engaging My PCR partners throughout the process to ensure that the content of the toolkit reflects their suggestions and feedback.



The process began with bringing in Kathy Redmond, a leading consultant in the CML field, to guide the strategy for the toolkit development. The Max Foundation and Kathy then reached out to four key patient advocate representatives from our partners in Latin America, South Asia, Asia Pacific, and Africa to make up a global steering committee to oversee the content creation of the toolkit. At CML Horizons in May of 2016, Kathy and The Max Foundation invited 35 advocates from partner organizations worldwide to participate in a focus group using the “World Café” model to generate content ideas and suggestions from the CML community. This information was then used to inform the final content of the first version of the My PCR Advocacy Toolkit, which will be officially launched in the first quarter of 2017. To ensure that the content was conveyed effectively, My PCR engaged Nucleus Global, a medical communications company, to produce the written copy, info graphics and visual design.

[A downloadable PDF of the toolkit is available on the mypcr.org website](https://mypcr.org), and hard copies were printed and shipped to partners in early 2017.

2. My PCR Grants

Central to the My PCR vision is continuing to foster and strengthen quality discussions between patients and physicians about the role of PCR testing in the effective monitoring of CML and region specific PCR related needs. To this end, in 2016 My PCR provided three different types of grants for partner organizations: Hematology Society Grants, PCR Materials Grants and World CML Day "Treat Your Physician" Grants.

In 2016, My PCR awarded a total of 44 grants to partners.

FIGURE 2: Number and percentage of My PCR grants awarded by geographical region.

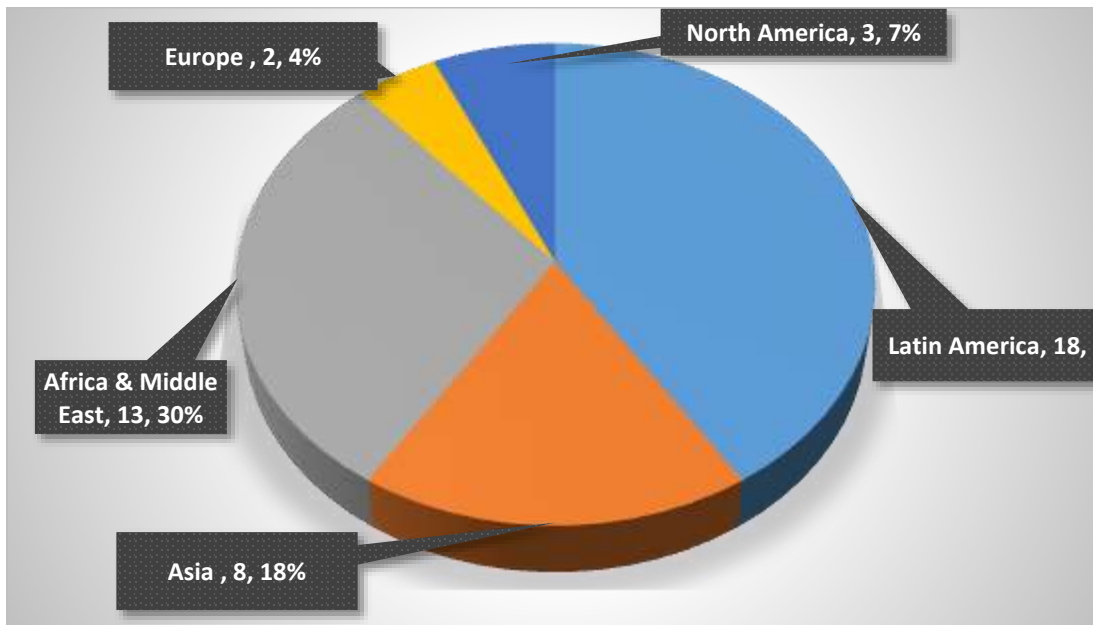
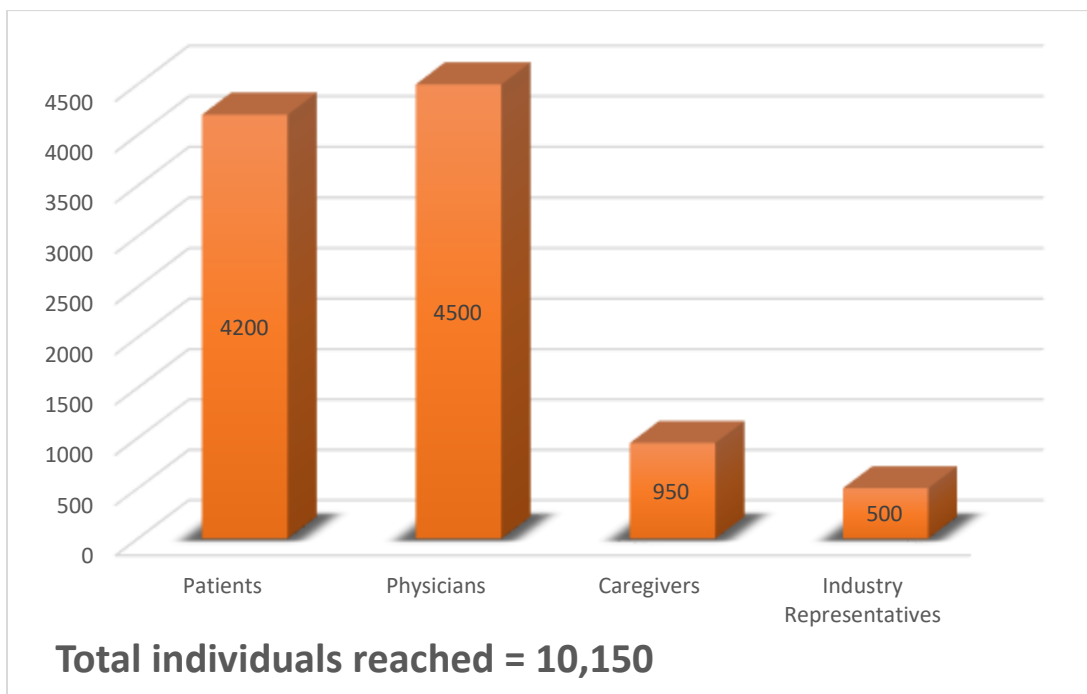


FIGURE 3: Number of individuals reached by My PCR grants.



Hematology Society Grants

Hematology Society Grants are designed to provide partner organizations with the opportunity to attend a local hematology society conference and represent the campaign through a booth. Representing the campaign at hematology society conferences is particularly valuable because it provides patient leaders with the opportunity to both educate others about PCR and learn from and talk with physicians, researchers and industry leaders about PCR as it relates to CML locally in their region.

In total, 7 Hematology Society Grants of up to US\$2,000 were awarded to partners of My PCR in 2016. Common themes that emerged from the feedback received from grantees after the conferences included a general consensus that the booths improved dialogue between physicians and patients, provided an important opportunity to network with industry representatives, and increased general knowledge among physicians, patients and industry representatives about PCR testing in the management of CML.

Hematology Society Conference Stats:

Partners that received a Hematology Society Grant	7
Patients Reached	2000
Physicians Reached	4000
Caregivers Reached	400
Industry Representatives Reached	500
Total Individuals Reached	6900
My PCR Campaign FAQs Distributed	2500
My PCR Campaign Stickers and Buttons Distributed	1500
My PCR Wallet Cards	500

Hematology Society Grant Recipients:

Country: Brazil

Booth at the Brazilian Hematology, Hemotherapy and Cellular Therapy Congress
Hosted by Associação Brasileira de Linfoma e Leucemia – ABRALE

Country: Guatemala

Booth at the Asociación de Hemato-Oncología (AHOG) Congress
Hosted by Asociación de Pacientes con LMC - ASOPALEU

Country: Israel

Booth at the Israeli Hematologists Annual Conference
Hosted by Israeli CML Patients Organization

Country: Kenya

Booth held at the Kenya Society of Hematology and Oncology Conference
Hosted by Henzo Kenya

Country: United States (3 grants awarded)

Booth at the European School of Hematology Conference on CML
Hosted by The Max Foundation, CML Busters, The National CML Society, and the CML Society of Canada

Hematology Society Grant Testimonial:

With help from My PCR, we are able to attend the Hematology Society Conference as an exhibitor. The Hematology Society Conference, is an event focused on the medical and pharmaceutical public, so is a great opportunity for the patients support association talk with the physicians and multidisciplinary professionals about the CML patient doubts and problems. The PCR advertisement material were very useful for the event audience, specialty for the physicians that need some easy and reliable information, about the PCR control, to share with their patients. Nowadays in Brazil the PCR test are only available for patients with private health service, and it is only accessible on the public system by laboratories donation. Facing this situation, ABRALE takes the opportunity that Hematology Society Conference offer to engage physicians on our advocates' actions to guaranty patient the right to have the PCR control supported by the government. Many physicians and multidisciplinary professional were very pleased to see that we are working together, in a global level, to help CML patients. Has the opportunity to share with the physician community these issues on event like this, it is important to strengthen the social control.

-Associação Brasileira de Linfoma e Leucemia – ABRALE

My PCR Event Grants

The second type of grant offered through My PCR in 2016 was the My PCR Event Grant, which provided funding of up to US\$1,000 to partners interested in hosting an awareness or educational event about PCR in their local community. The goal of this grant was to support local PCR awareness efforts among partners.

PCR Event Grant Statistics:

Partners that received a My PCR Event Grant	11
Patients Reached	2800
Physicians Reached	45
Caregivers Reached	395
Industry Representatives Reached	10
Total Individuals Reached	3250

My PCR Event Grants Recipients:

Country: Bangladesh
Partner: Bangladesh CML Supporting Group

Country: Burkina Faso
Partner: Groupe d Appui aux Survivants du Cancer

Country: India
Partner: Friends of Max

Country: Mexico
Partner: Asociación Mexicana de Leucemia y GIST, A.C.

Country: Pakistan
Partner: Kiran

Country: Nepal
Partner: Blood Cancer Society of Nepal

Country: Peru
Partner: Esperantra

Country: Peru
Partner: Luz de Esperanza

Country: Slovenia
Partner: Slovenian Lymphoma and Leukemia Patient Association, L&L

Country: Senegal
Partner: A.G.I.L du Senegal

Country: Togo
Partner: APSBES

My PCR Event Grant Testimonials:

Slovenian Lymphoma and Leukemia Patient Association organized informative event for patients and caregivers on 22 of September. The main aims of this event were to give support and information to the patients and their families and to increase public awareness about these diseases. The focus of the event was on CML from different perspective – from patient perspective, care giver/family member perspective and professional medical perspective. Ivan Žličar and his wife Fanika spoke about their experiences with the diagnosis, therapy and everyday life with chronic illness. Their story was full of optimism and hope that inspired others who are facing the same diagnosis.

-L&L Patient Support Group, Slovenia

Yes, thanks to the support provided by My PCR, we were able to host these three activities, which helped patients and caregivers understand what PCR is. The assistants to the presentation were able to ask questions and interact with the hematologist, who cleared all their doubts. The session of laughter therapy helped the patients relax and look at their disease with optimism and hope. We were also able to bring the informational material to many patients, and their comments regarding the material were positive. Esperantra is very grateful for the support provided.

-Esperantra, Peru

World CML Day “Treat Your Physician” Grants:

Initiated by the patient community in 2008, September 22 (9/22) has marked World CML Day because of its symbolic significance – the disease is caused by the change of chromosomes 9 and 22. On this day, patients across the globe come together to raise awareness about their needs to the general public, politicians, and medical professionals across the world. World CML Day is also a significant date for My PCR as it marks anniversary of the initial launch of the initiative on September 22, 2012.

In 2016, My PCR offered World CML Day “Treat Your Physician” grants to partner organizations, which offered up to \$300 for partners to bring a My PCR branded edible treat, such as a cake or pie, and an information poster about CML and World CML Day to their physician. The aim of this grant is to encourage patients and caregivers to give back to their physicians by bringing them a treat, and to create a space to engage in patient/physician dialogue around PCR testing.

The other component of this grant is the grantees are required to photograph the event with their physicians and share the photos with My PCR on Facebook and Twitter using the hashtags #TodayTogether #WorldCMLDay #MyPCR. In doing so, they contributed their voice to the World CML Day discussion over social media and brought the topic of PCR for CML diagnosis and monitoring to the table.

PCR Materials Grant Statistics:

Partners that received a “Treat Your Physician” Grant	27
Patients and Caregivers who Visited Physicians	475
Physicians that were engaged by partners	85



Photo featuring patient organization leaders in Morocco from AMAL and their local hematologists.

3. International and Regional Events and Conferences

My PCR was represented at one large international conference in 2016. In September, a My PCR booth was hosted by The Max Foundation, The National CML Society, CML Busters, and The CML Society of Canada at the European School of Hematology (ESH) – iCMLf International Conference in Houston, TX. The booth consisted of a branded 8' x 8' display, a full length branded tablecloth, and informational cards about My PCR, including My PCR sponsor names, for physicians to bring to their patients.

In addition, My PCR was widely represented through independently driven partner initiatives. **The campaign was represented at 9 regional meetings, congresses and patient/physician workshops in countries throughout Latin America, Africa, and Asia.** Campaign activities ranged from hosting a PCR booth to engaging patients and physicians in deeper discussion about the importance of PCR testing in the diagnosis and management of CML at patient organization meetings.

Additional 2016 Statistics:

Number of partner patient associations	75
Number of partner networks	3
Number of My PCR sticker translations	28
Number of countries represented by campaign partners	60
Total Number of people reached by My PCR through conferences and events	~12,250
Total number of individuals that benefitted from the campaign through a My PCR Grant	~11,000

Discussion:

2016 was both a year of growth for My PCR, in terms of partner engagement, and a year of strategic programmatic development around support for partner driven advocacy initiatives. My PCR saw a 25% overall increase in partner participation through grants, with a 20% increase in World CML Day “Treat Your Physician” grants alone compared to 2015. The continued growth in partner engagement is an encouraging indication of the value of the grant opportunities provided through My PCR. In the feedback we received from partners, it was emphasized that across of three grant types that they provided an effective platform to connect patient, caregivers, physicians, and industry representatives, and fostered critical dialogue about PCR testing in the management of CML. In addition, 12 new partners joined My PCR in 2016 increasing the partnership base by 20%, continuing the trend of growing the partnership base each year since the initiative’s inception in 2012.

Perhaps most notably, 2016 marked a shift towards taking a strategically tailored approach to the development of My PCR resources. Partner feedback that indicated a need for support for capacity building around advocacy efforts served as a guiding principle in the development of the My PCR Advocacy Toolkit. In 2017, My PCR is poised to focus on the implementation of the Toolkit by providing webinar trainings and advocacy grants to partners. The launch of the Toolkit conveniently also coincides with The Max Foundation driven PCR Gap Analysis initiative, a research project that will ultimately provide a landscape overview of the current state of PCR access worldwide, as well as barriers to access. This analysis is in direct response to feedback from partners in 2015, and at the “World Café” focus group at CML Horizons in 2016, that clear and concise mapping of access to PCR is critical in order for partners to effectively advocate for improved access in their countries.

Campaign Partners:

My PCR is designed to be a community run initiative. CML-focused groups and organizations have been integral to its success and progression of ideas. To read the complete list of My PCR partners, visit mypcr.org/partners/.

Photos:



Patient and physicians celebrating World CML Day with at "Treat Your Physician" grant in Sudan.



Slovenian Lymphoma and Leukemia Patient Association, L&L at their My PCR Awareness Event



Patients and physicians in Ukraine celebrating World CML Day with a My PCR "Treat Your Physician" Grant. The patient organization, Osanna, also arranged a patient education seminar during the celebration.



Patient advocate at the Henzo Kenya booth at the Kenya Society of Hematology and Oncology Conference.

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