



**Nomination for Elections
to the Steering Committee
"CML Horizons 2016-2017"**

Nomination for Elections to the Steering Committee "CML Horizons 2016-2017"



My organisation nominates me as a candidate for the election of the „CML Horizons“ Steering Committee.

The elections will be held at CML Horizons 2015, held 1-3 May 2015 in Barcelona, Spain. The term will be 2 years (2016-2017).

The new steering committee will consist of 6 elected representatives from the major regions plus three CML Advocates Network founders as permanent committee members.

Nominations must be done by member organisations of the CML Advocates Network.

Each organisation can nominate only one person for a defined region.

The nomination form needs to be received at info@cmladvocates.net by 14 April 2015.

Please make sure we confirm reception of your nomination.



My name: Gail Sperling

My role in the organisation: Sr Information Specialist, Information Resource Center

Organisation name: Leukemia & Lymphoma Society

Country: US

Organisation's official e-mail address: www.lls.org

My own e-mail address: Gail.sperling@lls.org

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
- Western Europe
- Central and Eastern Europe & West Asia

My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

In this last term, I replaced Gina Russo as Steering Committee representative. I have used the past year to get my bearings and begin to understand the organizations and efforts across the North American region as well as the international “reach” of CML Advocates.

I would use the 2016-2017 term to expand my involvement, take a more active role on the steering





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committee and encourage greater participation from CML organizations across the US and Canada. I am committed to ensuring that ALL patients with CML have access to current research findings, CML specialists, testing, support programs, education and advocacy.

About myself

I have been with the Leukemia & Lymphoma Society for 15 years, many of those years spent in the field as a Patient Services Manager. At last year's conference, I shared that I have been primarily Chapter-based and am well aware of the services/programs and the CML Busters in my local Southern California community.

During those years, I facilitated a local CML patient support group, the CML Busters. This time has been marked by profound changes in the CML landscape and I worked directly with patients, families and CML specialists in my community. This group is now almost 90 strong and growing every day. I have encouraged them to join CML Advocates.

My current position as an Information Specialist is a national position and has exposed me to CML activities and resources across the US and now Canada. In the last year, and actually more recently, I have reached out to connect with each of these member organizations. I feel strongly that there is an opportunity and clearly an obligation to work more collaboratively with these other CML organizations.

I look forward to growing in this role, sharing my expertise/experience and contributing to the activities of the CML Advocates Network.

Commitments and requirements for becoming a member of this Steering Committee:

- I confirm that I want to proactively contribute to the Steering Committee's activities
- I confirm that I want to proactively connect leukemia patient organisations in my region to the global CML Advocates Network's activities
- I agree to attend at least one face2face steering meeting per year, held at a major capital in Europe or the USA
- I intend not to miss more than 2 teleconferences during my term (approximately 8 teleconferences per year)
- I intend to respond to committee-related email communication latest within one week
- I confirm I have a good working level of English, both verbal and written



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My name: Ms. Sandra Shaw

My role in the organisation: Director

Organisation name: The CML Society of Canada

Country: Canada

Organisation's official e-mail address: info@cmlsociety.org

My own e-mail address: sandra.shaw@cmlsociety.org

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
- Western Europe
- Central and Eastern Europe & West Asia

My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

Ms. Shaw has asked us to nominate her on her behalf. Ms. Shaw's background in CML is extensive and covers all facets of the stakeholder's interests such as; the implications of a diagnosis of CML, the timely access to treatments, health information and general information about the disease. Sandra Shaw has an extensive background in governmental affairs both in Canada and in the U.S. from not only a government regulatory affairs prospect but as it regards to reimbursement policies at both the public and private payers level. We feel very strongly that Ms. Shaw's educational





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background in sciences as a geneticist and her candidacy as a Masters applicant in the McGill University Bioethics program through the McGill University experimental medicine department will be an asset to the steering committee team. Additionally, Sandra's well establish professional career in Marketing at all levels in the Pharmaceutical and health care industry provide her with a very well informed and unique view of the compelling issues and interests of CML patients throughout North America.

About myself

Ms. Sandra Shaw, B.Sc, M. Sc, Genetics, University of Guelph and McMaster University. Currently pursuing a Master's in Experimental Medicine, Specialisation Bioethics at McGill University in Montreal. Sandra Shaw is the founder, President and CEO of Fifth Element and previously to Global Chapter Research, Sales and Communication Services Inc. and was founder and owner of Chapter Three Group of Companies, all of which have been involved in market research, physician education programmes, sales support services and government relations services, all in the healthcare industry. Sandra has obtained an international experience in the healthcare marketing research industry through research into treatments, lifestyle, wellness and policy issues across all therapeutic areas and drug classes, including CML and TKIs. Over the last ten years, Ms. Shaw expanded her services to include strategic planning, as a participant in a number of key clients' products, as a session facilitator and a workshop and outcomes developer for key Canadian companies involved in healthcare, as well as healthcare organisations.

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My name: Rod Padua

My role in the organisation: President

Organisation name: Touched By Max, Inc.

Country: Philippines

Organisation's official e-mail address: www.touchedbymax.weebly.com

My own e-mail address: rod_padua@yahoo.com

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

I intend to showcase the best practices and innovations of the CML advocates in the Asia-Pacific. Primarily due to the geographical vastness, cultural differences and varying support of the respective governments, the CML groups in the region have customized the provision of their assistances according to their needs and the existing healthcare systems. The current concerns of the region also needs to be aired out so that they can be properly addressed. This is the primordial objective of Asia's Rising Sun, to cater to the needs of the patients in the whole region and





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admittedly, many solutions come from the global CML network.

About myself

I am a Steering Committee member of Rising Sun since 2011 and have initially work with Jan Geissler on the Junior CML portal of the cmladvocates.net website. I am an engineer by profession and a caregiver to my CML son for most parts of every day. He has been a survivor for 8 years now since he was 9 years old. Quite by chance, we have a substantial number of young adults and children at Touched By Max Philippines. Which is probably why this segment of the CML population is dear to my heart.

I foresee a very challenging environment for TKIs and other treatment interventions in the future, with the advent of generics and other treatment options in the Far-East. Patients are longing for a cure rather than a maintenance pill. Everybody must pitch in their own share of knowledge and experiences to make this happen. "Expert-patients" are now a by-word in the CML world. This recognition of expert-patients by the medical circle did not happen overnight. We created our own destiny, through the years, by proving that patients and advocates can complement the scientific experts in advancing the quest for solutions.

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My name: Zhengchen Liu

My role in the organisation: Founder, Chairman of the Board and CEO

Organisation name: New Sunshine Charity Foundation

Country: China

Organisation's official e-mail address: sunshine@isun.org

My own e-mail address: Zhengchen.liu@isun.org

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
- Western Europe
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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

I am from one of the few CML couples in the world. My wife is also a CML patient organization leader. I have very strong motivation to study CML and serve for patients.

In my term 2016-2017, I wish to contribute more for Capacity Building of patient organizations in Asia-Pacific region.

In many countries in Asia, the civil society is just at the beginning. Most patient organization





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founders had no experience of NGO or background of social work before their diagnosis. And this region is lack of support from umbrella organizations. We developed a capacity model of patient organizations, and I wish this could help to strengthen the capacity of patient organizations. We could provide visiting fellowships, education workshops, and advocacy education brochures, etc.

About myself

I was diagnosed as CML on December 4, 2001. After one month of my diagnosis, I set up Sunshine Marrow Donor Registry to help leukemia patients who need marrow transplant. On 2009, the New Sunshine Charity Foundation was established.

Last year we provided the first international marrow donation. A donor in our registry donated marrow for a US patient. Now we are one of the largest charity foundation who provide financial support to children leukemia patients. Every year we provided over 1 million US dollars for leukemia patients in China.

I have a keen interest in learning and research. I have been attending the American Society of Hematology Annual Meeting since 2011. From 2 years ago, we began to provide research support for doctors.

As the secretariat team of Rising Sun 2013, my foundation hosted the 4th Rising Sun Asia Pacific CML Advocates Meeting at Beijing. The number of participating countries increased 28.6% (from 14 to 18), and the number of attendee grown 64% (from 28 to 46).

My vision for the involvement of Asia-Pacific region: Capable Patient Organizations and Strong Network of Cooperation.

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My name: Pat Garcia-Gonzalez

single candidate – no voting required

My role in the organisation: President and Chief Executive Officer

Organisation name: The Max Foundation

Country: US based with focus on Emerging Countries.

Organisation's official e-mail address: info@themaxfoundation.org

My own e-mail address: pato@themaxfoundation.org

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
- Western Europe
- Central and Eastern Europe & West Asia

My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

I come to the Steering Committee of CML Advocates with a clear agenda: to represent the voice of advocates from Latin America and other emerging regions. I lead a dedicated team of advocates who are working hand in hand with patient leaders in the region to advance the needs of CML patients in Latin America. My team and myself have a track record of working closely aligned with CML Advocates and facilitate communications between CML advocates and Latin American organizations.





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About myself

I am one of the founders of The Max Foundation, a US based organization with global focus on cancer. The organization was created in the memory of my step son, Max, who was diagnosed with CML in 1988, before the era of TKIs, and who passed away in 1991 at the age of 17. Even though the mission of The Max Foundation is broad, CML has been a key focus of the organization, given our history. The organization has a mission focused on access to treatment and in 2001 the organization became the global administrator of the Glivec International Patient Assistance Program (GIPAP), a program of Novartis, and have since facilitated access to Glivec to more than 60,000 patients in 80 countries. Today The Max Foundation is involved in six partnerships that result in access solutions, including access to treatment and diagnostics for CML.

Additionally, for the past 10 years The Max Foundation has partnered with patients to form national patient support organizations and today the organization partners with 68 organizations from 58 countries through the Max Global Network.

In Latin America we have a dedicated team of 10 advocates who support access programs, adherence programs, educational programs, and awareness programs. We are the coordinators of LA LMC, a working group for leaders of organizations from the region. Our goal is to continue to advance the needs of people living with CML in Latin America, and to represent the needs of advocates from the region, as well as other Emerging Regions, in the CML Advocates network.

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My name: Bahija Gouimi

My role in the organisation: President

Organisation name: (AMAL) Association des Malades Atteints de Leucémies

Country: Morocco

Organisation's official e-mail address: amaleucemie@yahoo.fr

My own e-mail address: bahijagouimi@yahoo.fr

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

I have been nominated for the steering committee in order:

- To practice and share my skills in communication and participative management with global CML community
- To bring the reality of developing countries to developed countries





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- To introduce and represent CML Life Africa as a cofounder and president of African CML patient group
- To learn from the most successful experiences and best practice of other CML group across the world
- To be able to defend our project of building a structure to receive patients and their families
- To develop Advocacy work and make leukemia a priority of public health in Morocco

About myself

- Bahija Gouimi, was born in 1970 in Taza - Morocco, mother of three kids, teacher at high school since 1994. I am a patient living with leukemia since 2002, I stopped treatment since May 2011
- Founder and president of AMAL, the first CML group in Morocco and North Africa. Our objectives are: to raise awareness about leukemia, to organize advocacy activities to improve access to proper treatments to all CML patients in Morocco.
- Member of several NGO since 2000.
- Champion Arab area by the ICCCPO (International confederation of Childhood Cancer Parent organizations)
- Speaker at Siop Africa twice: Morocco 2006 and Tunisia 2008, at the ICCCPO Asia meeting (Indonesia 2007 and 2012, Sultanat of Oman 2008, Lebanon 2009), at the congress of Moroccan society of haematology
- Winner of the best practice poster at the CML Horizons 2009 and 2012
- Prize-winner of International Connectingroup Women's Network
- Member of steering committee of CALAMEA (Cancer Advocacy leaders Alliance of Middle East and Africa)
- Prize-winner of Women's Mentoring and Networking in Morocco
- Member of steering committee of CML Advocates Network (representative of Africa)
- Author of 2 books « Aches to live » published in France, September 2008 and « Ink cancer » published in Morocco, June 2012. The total recipes go to CML patients.
- Some articles in Moroccan and French newspapers, Interviews, television and radio programs
- Many celebrations, partnerships, programs, awards, ...

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Please make sure we confirm reception of your nomination.



My name: Ferdinand Mwangura

My role in the organisation: Chairman

Organisation name: Henzo Kenya

Country: Kenya

Organisation's official e-mail address: info@henzokenya.or.ke

My own e-mail address: fmwangura@gmail.com

Herewith I am nominated for the following region

- North America
- Asia-Pacific (incl Australia and New Zealand)
- Latin America
- Middle East & Africa
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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

Middle East and Africa are regions that still lag behind in the treatment and management of CML, given an opportunity at the Steering Committee I will address this issues with the urgency they deserve. To do this I will focus on 3 key areas:-

1. **Access to treatment:** To date, our region has failed to keep up with the rest of the world in access to treatment. It will be my priority to address this problem and have more people on





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treatment.

2. Patient support and education: I believe patient support as well as education is key in management of CML. I will use every effort to provide information that will empower people in our region.
3. Advocacy, Advocacy, and Advocacy: The more we are in this region the bigger our voice. It will be my agenda to have more patient advocates from Middle East and Africa.

About myself

I am a father of a 3 year old girl. I was diagnosed with CML in 2005. My journey has been very interesting full of learning and meeting people worldwide.

I am founder member of Henzo Kenya a CML support group. Henzo means love in Swahili.

17th September 2009, Henzo was officially registered with the Government of Kenya.

My growth in the advocacy world has seen me jump one hurdle after another, this valuable experience has enabled me acquire the necessary skills to address bigger challenges in life.

Just to share with you my latest success story:

1. I have successfully lobbied the Kenyan Government to provide our patients with Nilotinib as our 2nd line CML treatment. The negotiations are ongoing and very soon we will have our patients access this treatment. In a months' time we will have a big announcement on this.
2. CML monitoring in Kenya is now on another level thanks to affordability and availability of PCR testing as well as mutational testing.

Henzo Kenya is the leading advocacy group in Africa and I plan to share my experience in the region so as to help upcoming groups.

With this few remarks I would kindly like to be that bridge that will narrow the gap!

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My name: Rita O. Christensen

single candidate – no voting required

My role in the organisation: Chairwoman

Organisation name: LyLe – Patient group for Lymphoma and Leukemia

Country: Denmark

Organisation's official e-mail address: lyle@lyle.dk

My own e-mail address: rita@lyle.dk

Herewith I am nominated for the following region

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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

My motivation is to bring relevant information to patients with CML. I didn't get information about my disease at all, because there was no information at that time when I was diagnosed with CML in 1997.

As the chairwoman of LyLe – the Patient Group for Lymphoma and Leukaemia - and an author of my own book (Living the good life with CML), I'm often contacted from new patients, who need all the





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information about CML they can obtain, and my highest wish is to provide necessary guidelines and information of this specific disease.

About myself

I'm a CML patient, BMT-ed in 1997, with accelerated CML. I was on Hydrea and Interferon A until the BMT. The donor was my sister from Germany. I had 2 relapses, and then I got T-cells from my sister. The blood sample was very unstable - with many infections, and was in hospital the most of the time. I went on Glivec in 2003, because another relapse and I got better and could live life again. I went on Tasigna in 2010, as the blood samples were unstable again.

Today I'm on a "Stop Trial" since March 2013, and until now the blood samples are "negative/positive" all according to acceptance, but I'm doing fine and enjoy my "new life".

I'm a happy woman and have dedicated my life to people, who need all the experience, I have, and all the advice - I can provide to "bring them back to a life" they can accept and enjoy!

To me this is a task more than a request, as I feel strongly for my fellow patients. United we stand strong - that's it and that's that.....It might seem simple and a kind of naive - but to me it makes sense.

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My name: Jelena Cugurovic

single candidate – no voting required

My role in the

organisation: Member of the Steering Committee, PR & International Cooperation

Organisation name: CML Association of Serbia

Country: Serbia

Organisation's official e-mail address: cml@cml.rs

My own e-mail address: jcugurovic@gmail.com

Herewith I am nominated for the following region

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My motivation and contribution during my term 2016-2017 to represent my region, and to ensure involvement of my region in CML Horizons and the CML Advocates Network

CML association of Serbia has made strong connections with other associations from the Balkans region by helping in publishing materials, facing government and policy issues, learning and supporting each other in all aspects of advocacy work. Together we have been fighting with generic issues and created the Declaration of CML community. I would like to continue this work and to connect other advocates from Central and Eastern Europe & West Asia, because I think that we are





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facing similar problems. I strongly believe that united we can do more!

If elected I will seek to represent the interests of the region in the network ensuring that the voice of the region is heard.

About myself

I am a marketing manager, a CML advocate and most importantly I am a daughter of a CML patient. My journey in the CML world began in 2002 when my mother was diagnosed with CML. Since then I have been an active member of CML Association of Serbia, responsible for international cooperation, marketing & PR. When I joined CML Serbia it was at its beginnings and now we are a strong association with remarkable publishing activity, interactive website, good relationships with doctors and caregivers, strong lobbying position and are a member of the national commission for CML drugs.

We have worked hard on making strong connections with associations from Balkans region based on speaking the same language and facing the same issues.

I have been active in the international CML advocates network, specially focused on the generic drugs issue, because we were the first country in the world facing it. Also, I was very proud to welcome CML Horizons 2014 in Belgrade and help in its organisation. This year I am a member of the organisation committee for the CML Horizons 2015 in Barcelona.

My motive to run for the CML Steering Committee member is to bring together the region of Central and Eastern Europe & West Asia with all its differences from the rest of Europe and specificities and to represent them in the best possible way.

Commitments and requirements for becoming a member of this Steering Committee:

- I confirm that I want to proactively contribute to the Steering Committee's activities
- I confirm that I want to proactively connect leukemia patient organisations in my region to the global CML Advocates Network's activities
- I agree to attend at least one face2face steering meeting per year, held at a major capital in Europe or the USA
- I intend not to miss more than 2 teleconferences during my term (approximately 8 teleconferences per year)
- I intend to respond to committee-related email communication latest within one week
- I confirm I have a good working level of English, both verbal and written

