Today, Together

WORLD CML DAY TOOLKIT TRAINING

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WORLD CML DAY Toolkit 2015

KEY MESSAGE: TODAY, TOGETHER

• Today, together, WE can make World CML Day even more visible and engaging.

• The aim of this toolkit is to support you in making more people care and talk about CML.

• This toolkit includes customized messages for different audiences, artwork for posters and flyers, for print and online use and guidelines how to use all of them.
TODAY, TOGETHER: why?

**TODAY**
- Today covers the CML practical agenda for all audiences point of view:
  - Where we are
  - Facts
  - Needs
  - Best practices
  - Calls for actions

**TOGETHER**
- Together covers the CML community and emotional aspect, globally and in close networks around individuals.
  - We are a community
  - There is a support
  - Beyond the disease
Target audiences and messages

GENERAL PUBLIC
TODAY WE LIVE,
TOGETHER WE FIGHT

HEALTH CARE PROFFESIONALS
TODAY WE LISTEN,
TOGETHER WE HELP

PATIENTS & RELATIVES
TODAY WE TALK,
TOGETHER WE LIVE

POLICY MAKERS & GOVERNMENTS
TODAY WE ASK,
TOGETHER WE CARE
Today we live,
Together we fight
GENERAL PUBLIC
GENERAL PUBLIC: Today we live, together we fight

**Actions:**

- Teach general public about CML: CML is leukemia, a rare cancer!
- Inform the public about problems patients are facing.
- Call them to become part of World CML day!

**CML patients face a rare life challenge**

Yes, it’s leukemia, it’s cancer. But if treated effectively with recommended treatments, patients with chronic myeloid leukemia (CML) today can have a life expectancy similar to that of the general population. Less than two decades ago, CML was a guaranteed death sentence. Today, medicine has provided us with the weapon we need to live. But it’s still an ongoing fight: not all patients have access to the best available treatment and care, making CML their lifelong sentence. Join the battle against this rare challenge today and together with all of us. Help raise awareness on World CML Day 9/22. Learn more and show your support! **Today, Together**
GENERAL PUBLIC: Today we live, together we fight

Yes, it’s leukemia, it’s cancer.

But if treated effectively with recommended treatments, patients with chronic myeloid leukemia (CML) today can have a life expectancy similar to that of the general population.

While medicine has provided us with the weapon we need to live and enjoy a good quality of life, it is still an ongoing fight to help each patient access treatment.

Space for localization/inserting local organization’s story... for example: Eight here in Spain, there are XYZ patients who don’t want to struggle with CML and we are fighting to change that.

Join the movement for access to treatment for this rare cancer today and together with all of us and help raise awareness on.

Chronic myeloid leukemia (CML) is a rare cancer that is characterized by the uncontrolled growth of white blood cells in the bone marrow and the accumulation of those cells in the blood. Even though there has been a medical revolution in treating CML over the past decade, not every patient has access to the best available treatment and care. Those who have access struggle to live with CML as a chronic, life-changing disease. Without treatment, life expectancy is three years.

World CML Day
Initiated by the patient community in 2009, September 22 is World CML Day because of its symbolic significance – the disease is caused by the change of chromosome 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.

The CML Advocates Network
The CML Advocates Network is a global not-for-profit community run by patients to support patients. Launched in 2007 by four founding organizations, it now consists of more than 19 patient groups, offering support by sharing best practices, information, and advice for CML patient advocates. Find out more at http://chronicmyelonecises.net.
Today we talk,
Together we live

PATIENTS & RELATIVES
PATIENTS & RELATIVES: Today we talk, together we live

**Actions:**

- Teach patients and their relatives about World CML Day!
- Call them to raise awareness about CML by sharing their stories.
- Tell them that they are not alone in their fight, there are hundreds of people around the world in the same fight.

**We share your life challenges**

We aren’t just all talk. But that’s how it began. Because we raised our voices and spoke up about chronic myeloid leukemia (CML) and our challenges, living has become a reality. With the strong support of our families and friends, we have been able to share our experiences with others like us, bringing hope that a normal life is possible with the right treatment. So let’s keep talking, doing, and living, because while CML is part of our lives, it isn’t our whole life. Join our talk and share your life with us on World CML Day 9/22. **Today, Together**
PATIENTS & RELATIVES: Today we talk, together we live
Today we listen, Together we help

HEALTH CARE PROFESSIONALS (HCPs)
HCPs: Today we listen, together we help

Actions:

• Teach HCPs about World CML Day!

• Show them that you appreciate everything they are doing for patients.

• Show them what more they can do to help patients.

CML patients face a lifelong challenge, be a lifelong caregiver

A genetic change of chromosomes 9 and 22 is all it takes to change a life forever. But as a healthcare provider, you know that chronic myeloid leukemia (CML) isn’t the end. Thanks to the medical advances of the last two decades, you are able to guide your patients to a lifelong track of healing, listen to their concerns, and provide them with the best available treatment. Because of your care, CML is not a death sentence but a challenge that you and your patient can overcome together. Keep sharing your knowledge, listening, and helping: World CML Day 9/22. Today, Together
HCPs: Today we listen, together we help

CML? Let’s take control!

A genetic change of chromosomes 9 and 22 is all it takes to change a life forever. But chronic myeloid leukemia (CML) isn’t the end. Thanks to your help and the medical advances of the last two decades, you are able to guide us patients to a lifelong track of healing, listen to our concerns, and provide us with the best available treatment.

(Space for localization/dedication/local organization’s story... for example: Right here in Vietnam, our patient groups have supported... and we’ve been able to bring hope and normalcy to...)

Keep sharing your knowledge, keep listening, keep helping – today and together on

World CML Day

September 22nd (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 around the world.

The CML Advocates Network

The CML Advocates Network is a global network of patient groups and patient organizations, from over 100 countries around the world, working to educate patients, caregivers, and healthcare professionals about CML.
Today we ask,
Together we care

POLICY MAKERS & GOVERNMENTS
POLICY MAKERS: Today we ask, together we care

Actions:

• Teach policy makers & governments about CML: CML is leukemia, a rare cancer!

• Show them the problems you are facing and ask for specific actions regarding the issues you are facing.

CML patients face a lifelong challenge, they need lifelong care

Isn’t it a fundamental right for every human being to be able to live a decent life and enjoy a good quality of life? And yet, not everyone receives the care they need. Patients with chronic myeloid leukemia (CML) face the lifelong challenge of a chronic rare condition, and they must cope with a number of disparities such as non-availability of quality drugs or overpriced drugs, and lack of quality diagnostics and monitoring. But unlike CML, these difficulties do not have to be lifelong: you can change this. Strive to make things better, push for affordable and easy to access treatments for CML patients, and help them lead normal lives. Show you care and join the battle: World CML Day 9/22. Today, Together
POLICY MAKERS: Today we ask, together we care

Surviving cancer, enjoying a good quality of life – two fundamental rights!

Yet, everyday, patients with chronic myeloid leukemia (CML) right to receive the care they need – from access to quality, affordable drugs to optimal diagnostic and monitoring.

While surviving the disease is a lifelong challenge, the battle to receive the right treatment and care shouldn’t have to be. You can change this.

For local organizations, their story – for instance, Right here in Spain, our cancer patient organization has been working with the ministry of health to XYZ but more needs to be done in XYZ...and we keep fighting for..."

Help CML patients survive and be productive members of our society. Show you care and join the movement on.

World CML Day

Inaugurated by the patient community in 2008, September 22nd (32) 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.

The CML Advocates Network

The CML Advocates Network is a global nonprofit community run by patients, in support of 30 countries. Launched in 2007 by four founding organizations, it has contacts with more than 190 patient groups, offering support by hosting best practices, internships, and advice for CML patient advocates. Find out more at "http://cmladvocatenetwork.net"
POSTERS & FLYERS
POSTERS & FLYERS: How to use?

1. Pick the target audience you want to address (you can pick more than one)

2. Find appropriate poster on:
   http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/posters-7
   & appropriate flyer on:
   http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/flyers
   All available in PowerPoint, InDesign and PDF.

3. Translate them

4. Pick the photo which reflects your group the best on:
   http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/photos
   If none of the photos reflects your group, use any photo you find suitable!
POSTERS & FLYERS: How to use?

5. Put information about your organization on posters and flyers
6. Update flyers with the stories about your organization
7. Print poster & flyers
8. Hang posters in your office and everywhere you find appropriate (exp. doctors office, event place, …)
POSTERS & FLYERS: How to use?

10. Distribute flyers in your office, send them by mail, ...

11. Post e-versions of posters and flyers on your webpage, Facebook, Twitter, ... & call people to share them

12. Send them by email to the target audience (patients, doctors, nurses, government offices, media, ...)

AND:

13. Do not forget to share your translations with CML network and help other organizations speaking same language!

Send your translations to:

nicole@cmladvocates.net
POSTERS & FLYERS: Notes

- Posters and flyers can be used during the whole year not only for 22/9.

- Use them to raise awareness about CML and point out those issues patients in your country are facing in communications with different target audiences.

- When the World CML day 2015 passes the new World CML day 2016 is to come! Use these materials in 2016 too!
EVENT PLANNING
EVENT PLANNING: Before the event

Your team

- Choose your team, people who are going to help you in organizing the event.
- Give each one a role and expectations (e.g. logistics, communication with speakers, catering, media, taking photos,…) and choose a team leader.
- Give them specific timetables with deadlines for each task.
- Depending on the size of the event one person can have more roles.
- It is better to have less well organized people than more disorganized ones.
EVENT PLANNING: Before the event

The venue

• Choose the venue according to:
  - the needs of your audience
  - the topic of your event
• For events for fewer than 100 people choose cozy venues like conference rooms or theatres.
• Choose a venue that is easy to find and reach and has enough parking places.

• Check if the venue has all requirements you need:
  - Possibility to project videos
  - Stage for speakers
  - Internet connection
  - Provides food and beverages
  - Exhibit place for materials, …
EVENT PLANNING: Before the event

The program & guests

• Choose the topic of the event! It can be World CML Day or any other.
• Depending on the topic, choose the program and speakers.
• Contact speakers and check their availability. Tell them what you would like them to speak about.

• Give them a clear framework (time, content, audience expectations,…).
• Ask the speakers to send you their presentations and briefs at least 2 weeks before the event.
• Choose the host person of the event.
EVENT PLANNING: Before the event

Promotion

• Make a media toolkit with basic information about your event: where, when, who and why!
• Produce banners, posters, flyers with the above information and your logo (e.g. use posters for World CML Day).
• Do not forget to put the contact person.

• Advertise your event using different channels:
  - Put them on your website
  - Send invitations by email
  - Send invitations by regular mail
  - Post on Facebook, Twitter, …
  - Notify media about the event
## EVENT PLANNING: Timetable

<table>
<thead>
<tr>
<th>Time frame</th>
<th>Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 weeks before</td>
<td>- Create your budget</td>
</tr>
<tr>
<td></td>
<td>- Create event plan (event topic, target audience, speakers, sponsors,</td>
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<tr>
<td></td>
<td>hashtag, venue)</td>
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<tr>
<td></td>
<td>- Choose your team</td>
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<tr>
<td></td>
<td>- Book venue</td>
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<tr>
<td></td>
<td>- Choose and schedule speakers</td>
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<tr>
<td>7 weeks before</td>
<td>- Create event agenda (program of the event with times, topics and</td>
</tr>
<tr>
<td></td>
<td>speakers)</td>
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<tr>
<td></td>
<td>- Distribute tasks with timetables and deadlines to your team</td>
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<tr>
<td></td>
<td>- Begin preparing presentation materials (banners, invitations, save</td>
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<tr>
<td></td>
<td>the date cards, posters, flyers, PR text)</td>
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<td></td>
<td>- Take inventory of printed materials you want to give away (flyers,</td>
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<tr>
<td></td>
<td>booklets, pins,…)</td>
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<tr>
<td></td>
<td>- Choose vendors (designer, printer, audio visual and catering)</td>
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## EVENT PLANNING: Timetable

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</table>
| 6 weeks before   | • Design print and email invitations  
                        • Design all print materials  
                        • Build registration engine (online or telephone if needed) |
| 5 – 4 weeks before| • Deliver print mail invitations and email invitations (1\textsuperscript{st} blast)  
                        • Share save the date invitations via social networks  
                        • Post information about the event on your website  
                        • Start promoting your event  
                        • Update your e-mail signature with the event design |
| 2 weeks before   | • Send email invitations (2\textsuperscript{nd} blast)  
                        • Post some interesting statistics about CML on social network or photo and remind followers about the event  
                        • Ask sponsors and speakers to do the same (or just share your posts)  
                        • Remind the speakers to send you their presentations |
# EVENT PLANNING: Timetable

<table>
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<tr>
<th>Time frame</th>
<th>Tasks</th>
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<tbody>
<tr>
<td>5 -1 days before</td>
<td>• Confirm venue, catering, audio visuals, print materials</td>
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<td></td>
<td>• Review the presentations of the speakers</td>
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<td></td>
<td>• Prepare PR text for posting and send it to media</td>
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<tr>
<td></td>
<td>• Prepare information for posting on social networks</td>
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<tr>
<td></td>
<td>• Send email reminder of the event</td>
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<tr>
<td>EVENT DAY</td>
<td>• Refer to Event day Checklist</td>
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<tr>
<td>1 -2 days after</td>
<td>• Post photos from the event on social networks (1 day after)</td>
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<td></td>
<td>• Post how many people did attend and who was speaking</td>
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<tr>
<td></td>
<td>• Share a summary of key conclusions and quotes from speakers with a few images with the media.</td>
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<tr>
<td></td>
<td>• Debrief with the speakers, your team and sponsors</td>
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<tr>
<td></td>
<td>• Send Thank you emails to attendees</td>
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</tbody>
</table>
**EVENT PLANNING: Timetable**

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<th>Time frame</th>
<th>Tasks</th>
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<tbody>
<tr>
<td>7+ days after</td>
<td>• Enter event statistics in Event plan</td>
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<tr>
<td></td>
<td>• Summarize pros and cons of the event – what could be better</td>
</tr>
<tr>
<td></td>
<td>• Summarize the budget</td>
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**Note:** This timetable is not so strict. In many situations it is adoptable to the situation and country. But, trying to work according to this timetable will help you organize a good event.
EVENT PLANNING: How to incorporate World CML Day?

• You can plan the event with the main topic: World CML Day 22/9 or you can incorporate World CML Day in your event.

• Use the World CML Day logo in promotional materials of your event. It is available for download here: http://www.cmladvocates.net/world-cml-day-9-22/worldcmlday2015/wcmld-logo

• Use posters and flyers to inform target audiences of World CML Day:
  - Post posters on your webpage/social media channels
  - Hang posters and distribute flyers in the event room
  - Write statistical info about World CML Day in your posts.
  - Distribute pins you get from the CML Advocates Network (not available for World CML Day 2015).
EVENT PLANNING: How to incorporate World CML Day?

- Put a short presentation about World CML Day in your event agenda:
  - Tell the audience about World CML Day 22/9 and why it is important; how many people are there in the world with CML united on this day
  - Tell the audience about the CML Advocates Network


- Use #WorldCMLDay in your posts on social networks.
EVENT PLANNING: How to incorporate World CML Day?

- For more guidelines and information of how to incorporate World CML Day in your activities see:
  http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/communication-guidelines
SOCIAL MEDIA: how to use the WCMLD Toolkit

When you choose your social media channels, keep in mind 3 things:

• Your AUDIENCE
• Your GOAL
• Your TIMINGS
SOCIAL MEDIA: general rules

1) FIRST
Identify WHO are you going to speak with:
• General Public;
• Patients and Relatives;
• Healthcare Professionals;
• Policy Makers;

2) SECOND
Identify the MESSAGE you are going to use:
• Today we listen, Together we help - Healthcare Professionals
• Today we talk, Together we live - Patients and Families
• Today we ask, Together we care - Policy Makers
• Today we live, Together we fight - General Public

→ In this example: General Public
3) THIRD

Choose the right channels to communicate with General Public

See communication guidelines (p. 7):

http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/communication-guidelines

To communicate with General Public, the use of Social Media is rather efficient, namely FACEBOOK and TWITTER
SOCIAL MEDIA: Let’s focus on FACEBOOK (FB)

Do you have a FB page? If not, it’s the perfect moment to start one!
Start it now! Building a page in FB takes time!

Useful advice :
• Use your organization logo as the profile picture
• Use a picture with the World CML Day logo as well as the claim of your campaign (“Today we live, Together we fight”) as landscape photo
• The logo can be downloaded here: http://www.cmladvocates.net/world-cml-day-9-22/worldcmlday2015/wcmlD-logo
SOCIAL MEDIA: Let’s focus on FACEBOOK (FB)

• Prepare the approach of Sept 22 by sharing small messages. Try to use the messages in the format of an image. Images communicate better, especially when you are talking with General Public; try to use images provided by the CML Advocates Network to create a global and unified campaign!

   See: http://www.cmladvocates.net/download/world-cml-day-922/world-cml-day-toolkit-2015/photos

• Start from the beginning by explaining in a very simple way what CML is and why we celebrate World CML Day on the Sept 22. Use a Philadelphia chromosome image to communicate the mutation

• Try to post your messages on Wednesdays or Thursdays between 10 am and 3 pm or after 9 pm
SOCIAL MEDIA: Let’s focus on FACEBOOK (FB)

- If you have any local statistics on CML, post them
- Share testimonials of patients living with CML and post their story with a picture
- On 09/22 do something DIFFERENT on FB, e.g. share a film, a cartoon, or an interesting campaign that will make people interact with you; if you do not have a film, use the ones in English provided by the CML Advocates Network (https://www.youtube.com/watch?v=8ne_HjZrW_Q)
- You must save time to dedicate to FB on the Sept 22. If your campaign is interactive, you must be available to answer the questions placed
- Try to place questions on Facebook to interact. Remember that you are talking to General Public, so most of your audience won’t have much information on CML → keep it simple, try to avoid technical terms!

Example of questions you can share to interact with the audience:
“Do you want to send a message to patients with CML?”
SOCIAL MEDIA: Let’s focus on FACEBOOK (FB)

- If you do, please send it to us and we will share it on FB, because TODAY we are TOGETHER!
- Ask people to share your page to raise awareness about the disease. Start by asking your friends, relatives and your list of contacts to share the page. Ask for their help to carry the message forward. Try to identify well-known bloggers, key opinion leaders and websites to share your page.
Not everything finishes on Sept 22!

- If you have organized an event use Facebook to post its pictures; call people to speak about what they have learned during the event …
- Read carefully all the comments after the event – you can learn a lot from them!
- Look carefully at the statistics: how many likes, comments, shares – next year you will want to improve!
SOCIAL MEDIA: Hashtags #

• Hashtags are keywords that when followed by # develop in hyperlinks and are indexed in search engines.
• This facilitates the research and analysis of shares on this topic.
• Hash tags for a specific campaign serve as suggestions or guide for all those who want to share posts on the topic.
• Hashtags suggestions for World CML Day 2015:
  • #TodayTogether
  • #CML2015
  • #September 922
  • #WorldCMLDay
  • #ChronicCancro
HAPPY World CML Day!

If you have any questions regarding the World CML Day Toolkit or need any advice, please do not hesitate to ask:

Jelena: jelena@cugura.rs
Sofia: sofiasacardoso@apcl.pt
Nicole: nicole@cmladvocates.net

or the representative of your region!
Thank You!