CML HORIZONS

HYBRID MEETING 2024

CML ADVOCACY • LEARN, SHARE, GROW

22ND INTERNATIONAL
CONFERENCE FOR ORGANISATIONS
REPRESENTING PATIENTS
WITH CML

WHO IS WHO

World CML Day
22 SEPTEMBER

CML ADVOCATES NETWORK

Vilnius, Lithuania
24–26 May 2024

CML HORIZONS 2024 • Welcome logistics information
24th to 26th May 2024 • Radisson Blu Lietuva Hotel

Dear Delegate,

It is with great pleasure that the CML AN Steering Committee and the CML Advocates Network welcome you to the 22nd CML HORIZONS 2024 in Beautiful Vilnius!

Lidija, Marija & Nikola from our management team are available throughout this conference to help you. As this letter contains some important and helpful information, please take the time to read it carefully.

HOTEL

Hotel: Radisson Blu Lietuva Hotel

Address: Konstitucijos Av. 20, Vilnius, LT-09308

Tel: +370 5 272 6272

Please note below the times you may check in and out of the hotel:

Check In: 15.00 — **Check Out:** 12.00
We are trying our best to allow early check-in and late check-out. However, this will depend on availability of rooms, thus it cannot be guaranteed.

Dialling room to room: Room number.

To dial for **room service: 555**

Gym: The Gym is located: Ground floor (0) open 24/7

Location and Names of Bars/Restaurants within the hotel, with opening & closing times:

- **Piazza Restaurant at hotel:**
  Monday to Friday 11:30 am - 10:30 pm
  Weekends and Public Holidays 5:00 pm - 10:30 pm
  Lunch Monday to Friday 11:30 am - 2:00 pm
- **Lobby Bar at hotel:**
  I-V 10:30AM - 11:00PM,
  VI-VII 11:00AM - 11:00PM
- **SkyBar at hotel - 22nd floor**
  VII-IV 6:00PM - 12:00AM
  V-VI 6:00PM - 2:00AM

For Steering Committee members, Speakers, and first delegates who are on full scholarship: In agreement with the Steering Committee your flights have been booked for you, therefore all nights depending on flights between the 23rd to 26th of May are covered. Also, accommodation and breakfast have been paid for you in advance. You will however, need to provide the hotel with a credit card at check-in to guarantee all incidental costs room service, bar and mini-bar, laundry, Internet, telephone etc. These costs are payable at check-out.

For Second delegates: The 800 Euros Conference Fee covers up to 4 nights of your stay at the Radisson Blu Hotel Lietuva. Please be aware that you will need to pay any additional night upon check-in, as well as the upgrade cost to a double room if required. Accommodation and breakfast on the conference days have been paid for you in advance - you will, however, need to provide the hotel with a credit card at check-in to guarantee all incidental costs – room service, bar and mini-bar, laundry, telephone etc. These costs will not be covered by us and are payable at check-out. If you need to pay dinners for your partner it will be paid on spot.

For Pharma representatives: You will need to pay your accommodation directly at the hotel – please provide the hotel with a credit card at check-in to guarantee all your payments (room charges and incidental costs like room service, mini-bar, and others).

BREAKFAST

Breakfast will be available for you at Riverside restaurant, which is located on ground level (0 floor). Breakfast is served on weekdays from 06.30 am until 10.30 am and on weekends from 6.30 am until 11.00 am. Please make sure you have enough time to have your breakfast and be on time for the beginning of the sessions!

CML HORIZONS HOSPITALITY DESK

Should you experience any problems or require changes in itinerary please contact Lidija, Marija or Nikola either at the Hospitality desk or on the mobile number below:

Lidija Pecova: Mob: **+389 78 388 235**

Marija Stefkova: Mob: **+389 77 859 659**

Nikola Nikolov: Mob: **+389 70 349 924**

MEETINGS

Inside your conference pack, you'll find a comprehensive agenda detailing all the exciting events lined up for this year's conference. Your name tag also contains a detailed schedule for easy reference. The conference area is conveniently situated on the 1st Floor of the Radisson Blu Lietuva Hotel.

Your **valuable feedback** has been taken into account, and this year, we're thrilled to introduce numerous smaller workshops and breakout sessions. These **sessions will be held** in the following **meeting rooms: Alfa, Omikron, Iota, Omega, and Tau**.

We're kicking off the conference on **Friday, May 24th,** with a **"CML 101" session at 10:00 AM**. This session is essential **for first-timers** and serves as a valuable refresher for seasoned attendees. Following that, we'll dive into **Regional Sessions at 10:45 AM**. Be sure to check your program for the respective room locations.

Get ready for an enriching and engaging experience at CML HORIZONS 2024!

PARTICIPANTS

The conference is a hybrid event, with approximately 120 registered participants, along with additional virtual attendees. Regular delegates can be easily identified by their GREY lanyards. Members of the CML AN Steering Committee, Special Advisors, and Management team will be distinguished by their YELLOW lanyards. Speakers will wear BLUE lanyards, while representatives from pharmaceutical companies will carry ORANGE ones.

INTERNET

Instructions to access the free WIFI: To access the internet no code needed.

DEPARTURE TRANSFERS

If a departure transfer has been requested, a departure notice with pick-up time at the hotel will be written at flip-chart at hospitality desk. Please be in the hotel lobby at least 20 minutes before the transfer.

DINNER ARRANGEMENTS

Friday, 24th May - Will be at the hotel starting at 19:30 with reception at the lobby of the conference area on level 1 followed by dinner.

Saturday, 25th May - we will depart from the hotel at 19:00 where we will go to the City Hall for our offsite dinner.

GROUP PHOTO

Group photo will be taken on **Sunday at 10:30** in the main conference room.

ADDITIONAL EVENTS

Sunday 26th May

After the conference ends on Sunday at 14:15, we are offering a 5 hour Guided City & Lake Tour. Registration is required as the number of seats is limited. If you have - or have not yet registered and your plans have changed, please let the team at the hospitality desk know. Buses will leave the hotel at 14:20 sharp - please meet in the lobby of the Hotel.

MONEY

The currency in Lithuania is the Euro.

FEEDBACK FORM & ATTENDANCE CERTIFICATE

Feedback Form: CML Horizons is now in its twenty-second year, and our commitment to meeting the community's needs remains unwavering! Your critical feedback is of utmost importance to us. We kindly request that you promptly complete the feedback form by scanning the provided QR code.

Additionally, Lidija will email you the conference feedback link shortly after the event, along with the attendee certificates. Your timely response and participation are greatly appreciated.

Attendee Certificate: We will send you the attendance certificate electronically by email after the conference. You can contact Lidija at: lidija@cmladvocates.net for further information.

Powered by INSIDER ID™
CONSULTING & RESEARCH

GETTING FROM HOTEL TO THE CITY CENTRE

The Radisson Blu Lietuva is only a 10-minute walk from Vilnius' intriguing Old Town, a fine display of Lithuanian architecture and tradition. A total of 1,487 buildings comprise this UNESCO World Heritage site that exemplifies the Gothic, Renaissance, Baroque and Neoclassical movements. The business and commercial sections of the city make up the New City Center, with its modern architecture and style. Check out some of our suggestions for nearby attractions below.

Vilnius

Nestled in the heart of Lithuania, Vilnius is a captivating blend of rich heritage and modern charm, beckoning visitors to explore its enchanting streets. As the capital city, Vilnius boasts a tapestry of historical landmarks and contemporary marvels, inviting travelers to embark on a journey through time. From the majestic Gediminas Tower overlooking the city to the quaint cobblestone streets of the Old Town, every corner of Vilnius tells a story of its past. Navigating Vilnius is a breeze, thanks to its efficient public transportation system and pedestrian-friendly pathways. Whether you're wandering along the banks of the Neris River or exploring the vibrant neighborhoods, Vilnius enchants at every turn. In Vilnius, history and modernity intertwine seamlessly, creating a dynamic cityscape that captivates the imagination and leaves a lasting impression on all who wander its streets.

Main attractions and surroundings:

Gate of dawn

Join people from around the world to make a special pilgrimage to the Gate of Dawn, one of the most religiously significant places in Lithuania.

Vilnius Cathedral

Vilnius Cathedral holds many notable works of art from the 14th through the 19th centuries, ensure you see the recently discovered frescoes in the underground chapel and the famous Sapiega Madonna.

Vilnius old town

Slip inside what were once the defensive walls to keep intruders out and discover the stunning Old Town of Vilnius. When you enter it, you feel as if you're back in the Middle Ages.

Gediminas castle tower

If you're looking for the best view of Vilnius, the Gediminas Castle Tower is a must-visit. Climbing up the narrow steps, discover more about the history of Vilnius and the Grand Duchy of Lithuania as well as a variety of historical artifacts. At the top, a breathtaking panorama of the city awaits.

Lukiškės prison 2.0

This prison-turned-venue was guarded by high fences and barbed wire for over a century. Now home to 250 creators and artists, you can enjoy a drink, a concert, or take a tour. The location easily transforms for different events and has even served as the backdrop for Stranger Things season 4.

Republic of užupis

Moving away from its troublesome past, the smallest district in Vilnius has blossomed into a hub of artists, intellectuals, and entrepreneurs. Uncover the district's fascinating history and don't miss out on the Swing of Destiny and the Mermaid of Užupis under the Užupis Bridge.

Welcome to CML Horizons 2024 at the Radisson Blu Hotel in Lietuva and Vilnius for CNL Horizons 2024! We extend our warmest greetings and wish you a delightful stay. As we embark on this conference journey together, our aspiration is for it to be a source of invaluable educational insights and create unforgettable memories for each one of us this year.

Warmest regards,

Your CML Steering Committee & Organising Committee

Agenda

24 – 26 May 2024

DAY 1 • FRIDAY • May 24th

10:00 - 10:45 *CML 101 - Dr. Van Etten (Virtual) & Jerry Clements*

10:45 - 11:45 *Regional Sessions*

- Africa Middle East Asia - room Omikron
- Asia and Pacific - room Omega
- Eastern Europe - room Iota
- Latin America - room Tau
- North America - Garden
- Western Europe - main conference room

12:00 - 13:00 Lunch

13:00 – 13:45 *CML Horizons 2024 Grand Opening*

- Welcome to Lithuania
  Speaker: Šarūnas Narbutas - 10 Minutes
- Opening of CML Horizons
  Speaker: Rod Padua - 10 Minutes
- Memories and Minute of Silence
  Speaker: Giora Sharf - 2 Minutes
- Update on CML AN Projects & Strategic Plan
  Speaker: Denis Costello - 18 Minutes

13:45 – 15:15 *Advocacy #1: Best Practices*

Chairs: Jana Pelouchová and Eunice Orekha

1. Medical Mentoring, A Heart Keeper - KBDCA, *Jung Suk Park*
2. Advocacy for CML During Challenges - Drop of Blood, *Nataliia Lopina*
3. CML Awareness Tea Parties, CML Zimbabwe, *Loretta Willimas*
4. Let's Show the healthy CML Survivors - Club Zero, *Yujin Hong*
5. Addressing Health Inequities through social participation in Brazil - ABRALE, *Catherine Moura*

CML HORIZONS
HYBRID MEETING 2024
CML ADVOCACY • LEARN, SHARE, GROW
22ND INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PATIENTS WITH CML
CML ADVOCATES NETWORK
Vilnius, Lithuania
24–26 May 2024

15:15 – 15:45 Coffee Break

15:45 – 17:45 *Medical Session #1:*
TFR Insights: A Comprehensive 360° Perspective

Chairs: Jerry Clements and Nigel Deekes

1. Predictors of Successful TFR what have we learned - Drs perspective: *Andreas Hochhaus - 20 minutes*
2. Navigating the Future After TFR Failure: Second Attempts and Beyond: *Jorge Cortes - 15 minutes*
3. TFR Risk Analysis - A Patients Perspective
   Bahija Gouimi & Nigel Deekes - 7 minutes each
4. Dose Reduction to TFR
   Daniela Žáčková - 15 minutes
5. TFR Monitoring and Protocols in LMICs (Low - to Middle - Income Countries) *Amma Benneh - 15 min*
6. How Can a Nurse Support Patients on TFR *Irene Caballes - 15 mivnutes*

Q&A
30 minutes

17:45 – 18:30 *Poster Palooza: Interactive Presentation, Networking & Conversations*

19:30 Dinner at Hotel

DAY 2 • SATURDAY • May 25th

08:45 – 11:00

Medical #2: 'Meet the Expert' Session

Gather in the main conference room for an introductory remarks and workshop instructions on group rotations.

Group 1 - room Eta
Navigating Side Effects: Expert Strategies for Effective Management
with: Nurse Specialist Irene Caballes and
Monitoring Cardiovascular Health in CML Patients Receiving TKI Therapy
with Nataliia Lopina - 60 min incl. open discussion

Group 2 - room Omega
Generics and Drug Interaction Perspective
with: Nick Duncan - 60 min incl. open discussion

Group 3 - room Omega
Treatment Choices Unveiled: Decoding Patient - Doctor Decision Dilemmas
with: Daniela Žáčková & Andreas Hocchaus
60 min incl. open discussion

Group 4 - room Eta
Treatment Choices Unveiled in LMIC's: Decoding Patient - Doctor Decision Dilemmas
with: Amma Benneh & Eunice Orekha
60 min incl. open discussion

Group 5
main conference room
Exploring CML Perspectives in Spanish
with: Jorge Cortes
2nd Hour will be joined by *Irene Caballes:* Navigating Side Effects: Expert Strategies for Effective Management and *Nataliia Lopina*: Monitoring Cardiovascular Health in CML Patients Receiving TKI Therapy
2 hours incl. open discussion

11:00 to 11:30 Coffee break

11:30 – 13:00

Advocacy session #2: Empowering Advocacy: Strategies and Collaborations

Breakout and workshops - Take 1
(Split to 4 groups and switch one time after 45 minutes.)

Workshop 1
main conference room
Know Your CML App Workshop: Unlocking its Potential for Advocacy
Speaker: Nikola Nikolov & Denis Costello - 45 min workshop getting to know the App

Workshop 2 - room Eta
Utilising Big Data for CML: The Harmony Project Updates and challenges.
with: Eglys Gonzalez virtually and Jan Geißler
45 min workshop

Workshop 3 - room Iota
Advocacy in Action: Global Access To Treatment & TFR Support Program by The Max Foundation
Speaker: Pat Garcia - Gonzalez - 45 min workshop

Workshop 4 - room Omega
Best Practices: How to Engage with Pharma
Speaker: Advocate: Jana Pelouchová &
Pharma: Beatrice Baudino - 45 min workshop

13:00 – 14:00 Lunch

14:00 – 15:45

Medical Session #3: Innovations in CML Prognostics and Treatment

Chairs: Giora Sharf and Catherine Moura

1. AI Revolution in CML Prognostics
   Speaker: Sin Tiong Ong (Virtual) - 20 Min plus Q&A - 10 min
2. Innovative Treatment - What's on the Horizon
   Speaker: Jorge Cortes - 20 Min
3. Challenges of Current Front - Line Treatments
   Speaker: Daniela Žáčková - 15 Minutes
4. New Data on First Line Treatment in CML
   Speaker: Andreas Hochhaus - 15 min

Q&A
15 minutes

15:45 – 16:15 Coffee break

16:15 – 17:45

Advocacy session #3: Empowering Advocacy: Strategies and Collaborations

Breakout and workshops - Take 2

(Split to 4 groups and switch one time after 45 minutes.)

Workshop 1
main conference room
Know Your CML App Workshop: Unlocking its Potential for Advocacy
Speaker: Nikola Nikolov & Denis Costello - 45 min workshop getting to know the App

Workshop 2 - room Eta
Utilising Big Data for CML: The Harmony Project Updates and challenges.
with: Eglys Gonzalez virtually and Jan Geißler
45 min workshop

Workshop 3 - room Iota
Advocacy in Action: Global Access To Treatment & TFR Support Program by The Max Foundation
Speaker: Pat Garcia - Gonzalez - 45 min workshop

Workshop 4 - room Omega
Best Practices: How to Engage with Pharma
Speaker: Advocate: Jana Pelouchová &
Pharma: Beatrice Baudino - 45 min workshop

19:00 OFFSITE DINNER *Meet at lobby for departure*

DAY 3 • SUNDAY • May 26th

9:00 – 10:30

Advocacy Session #4: Elevating Advocacy - Bridging Gaps

Workshop 1
main conference room
Empowering Healthcare Change - Makers
with: Roi Shternin

1. Cultivating Resilience
2. Mastering Storytelling
3. Startup Agility

Workshop 2 - room Eta
Digital Tools for Managing Your “Patient Organisation”
with Paula Capparelli

10:30 – 10:40 Group Photo in the main Conference Room

10:40 – 11:00 Coffee break

11:00 – 12:30

Advocacy #5: New channels of communication

Chairs: Rod Padua and Jelena Čugurović

1. How to Reach Out to and Empower Young Patients
   Speaker: Ana Amariutei (Virtual) - 20 min plus Q&A - 10 min
2. Building an Online Patient Community
   Speaker: Liat Rotem Melamed (virtual) - 20 min plus Q&A - 10 min
3. Increasing your Social Media Footprint
   Speaker: Roi Shternin - 20 Min plus Q&A – 10 Min

12:30 – 13:15

- Report from Regional Sessions and Presentation of New SC Members
  Moderated by Denis Costello
- Best Poster Award, Closing and Farewell
  Giora Sharf

13:15 – 14:15 Lunch

14:15 *CITY TOUR Meet at lobby for departure*

CML HORIZONS
HYBRID MEETING 2024

For full Who is Who profiles visit link:
https://cmlhz.cme-congresses.com/
(Door “Who is Who)

or scan the code:

Management team

Denis Costello

CML Advocates Network

Spain

How to contact me:

Email: denis@cmladvocates.net
Twitter: @rarecare

Lidija Pecova

CML Advocates Network : Head of Member Relations, Events & Programme Manager

HEMA-ONKO: President

Macedonia

How to contact me:

Email: lidija@cmladvocates.net
Mobile: +389 7838 8235 (WhatsApp, Viber & Telegraph)
Facebook: Lidija Pecova;
Instagram: lidijapecova
Twitter: @lidijapecov;
LinkedIn: Lidija Pecova

Marija Stefkova

CML Advocates Network

Macedonia

How to contact me:

MPN: doneva@mpn-advocates.net
CML: marija@cmladvocates.net
Facebook:
facebook.com/doneva.be
LinkedIn:
linkedin.com/in/marija-stefkova-358aa8187/

MY STORY:

’m Denis Costello, the Executive Director of CML Advocates Network. I joined the network in September 2019 and it has been a very exciting journey to be with all of you. I’m feel very honored to serve such a dynamic and motivate group of global advocates.

Before joining CML Advocates Network I spent over 10 years working with another patient organization called EURORDIS, the European Organisation for Rare Diseases. My role while there was connected with Digital Communications and patient empowerment in the use of digital technologies. I was also part of the team who founded and managed Rare Disease Day.

Along with the rest of the team I am happy to listen and learn from your advocacy work so that we can incorporate your needs into our global efforts through our many projects, our Community Advisory Board and World CML Day as well as of course for our CML Horizons Congress.

ABOUT MY ORGANISATION:

The CML Advocates Network is an active network specifically for leaders of Chronic Myeloid Leukemia (CML) patient groups, connecting 126 patient organisations in 93 countries on all continents. It was set-up and is run by CML patients and carers. Its aim is to facilitate and support best practice sharing among patient advocates across the world.

MY STORY:

I was born in Skopje and lived in Australia for most of my life before moving back to Skopje in December 2014. In my corporate career, I gained extensive experience in the nonprofit sector. A notable achievement was my collaboration with Suicide Prevention Australia and Australia’s representative to the UN Global Compact. The experiences I gained helped me understand the importance of supporting meaningful causes.

Having taken a short break, I was eager to apply the skills and knowledge I had acquired in the corporate and non-profit sectors in Australia to my local community in Skopje. It was at this time that I met Jan and Giora at a PAWG meeting. Shortly after, an opportunity arose for me to join the CMLAN team. CMLAN connects 128 patient organizations in 93 countries, and it is hosted by the “Leukemia Patient Advocates Foundation” (LePAF).

Drawing upon my experiences and passion for helping others, I founded HEMA-ONKO, Macedonia’s only cancer association that supports cancer patients and caregivers. The aim of HEMA-ONKO is to provide a support network and resources for individuals and families affected by cancer in Macedonia. Through various initiatives and programs, we strive toimprove the lives of those impacted by cancearly detection, prevention, and treatment options.

ABOUT MY ORGANISATION:

As the Head of Member Relations, Events, and Programme Manager on the CML AN team, I have a multifaceted role that oversees a wide spectrum of responsibilities. Among my primary responsibilities is membership management, where I cultivate a cohesive community of members and facilitate their active participation and engagement. This can be achieved by fostering a sense of belonging and encouraging members to contribute to our mission.

Also, I manage the CML Horizons Conferences and other events. These events are significant gatherings that bring together experts, professionals, patient advocates and individuals affected by CML. My goal as the Event Manager is to ensure the seamless execution of these momentous gatherings. I strive to provide support and create an enriching and impactful experience for everyone.

I also spearhead projects like CML Life, which provides information, resources, and support for people with CML. This initiative aims to provide valuable resources and foster a sense of community for people affected by CML. My responsibilities also include administration and HR functions to ensure smooth operations within CML.

Within the programme framework, my tasks also encompass planning, executing, and monitoring international and European projects. Ranging from educational programs that aim to raise awareness and provide information about CML to research initiatives that contribute to knowledge advancement in the field. All of these projects fall under the purview of the CML AN, and I am dedicated to driving them forward with passion and commitment.

I am fully committed to our organisation’s success and impact. I strive to improve the lives of those affected by CML through strategic planning, meticulous execution, and an understanding of the needs of our members.

MY STORY:

My name is Marija Stefkova and I grew and live in Skopje, Macedonia.

After loosing my grandfather from prostate cancer, I felt a profound urge to make a difference, for everyone battling cancer. In search of a way to contribute, I decided to volunteer at HEMA Macedonia. During my time at HEMA, I met Lidija who introduced me to the MPN Advocates Network where I started 2 years ago. Through these challenging times of my grandfather ‘s illness, volunteering at HEMA and working with the MPN Community not only allowed me to make a difference in the lives of those in need but also led me to another remarkable experience.

Last year, as the CML Advocates Network team grew, I joined the team and started assisting with the communications part of the organisation.

ABOUT MY ORGANISATION:

As the Communications Manager at CML AN, I am responsible for crafting and delivering compelling and consistent communication strategies that resonate with our audience. My role is all about ensuring that CML AN’s messages are not only clear and cohesive but also effective. I work to keep our team informed and aligned, while also engaging with the CML community via different social media platforms to showcase the organisation’s achievements, values, and innovations. In this dynamic role, I’m committed to helping CML AN tell its story and connect with the worldwide community.

Nikola Nikolov

CML Advocates Network

Macedonia

How to contact me:

Email: nikola@cmladvocates.net
Mobile No: +389 7034 9924
Available on WhatsApp and Viber

MY STORY:

I grew up in Skopje, 23 years old, working as a Membership & Programme Assistant for the CML Advocates Network for the past year. I am also currently studying social sciences and social politics. My goal is to continue growing and developing within this network to provide assistance to patients affected by CML.

ABOUT MY ORGANISATION:

The CML Advocates Network is an active network specifically for leaders of Chronic Myeloid Leukemia (CML) patient groups, connecting 126 patient organisations in 93 countries on all continents. It was set-up and is run by CML patients and carers. Its aim is to facilitate and support best practice sharing among patient advocates across the world. The CML Advocates Network is formally hosted by the “Leukemia Patient Advocates Foundation“ (LePAF), a global patient-led non-profit foundation registered in Switzerland connecting leukemia patient organizations on all continents to strengthen their advocacy work. For more information visit: www.cmladvocates.net

Sandra Pavlović

CML Advocates Network

Serbia

How to contact me:

sandra@cmladvocates.net;
academy@lepaf.org;
Phone: +381652463925
Facebook

MY STORY:

Back in 2006, Sandra had a child suffering from a rare disease, and although her life has changed entirely, it turned out that this further determined her professional path. Sandra has a long term experience as a patient advocate working as a President of the DEBRA Serbia association since 2010, and a Vice President of the National organisation for rare diseases of Serbia since 2013. Among other responsibilities and fundraising-related activities, she has organised many events such as conferences, panel discussions, round tables and awareness days, she also participated in working groups related to the amendment of various laws and regulations in the health and social care system in Serbia and related governmental bodies. Sandra has been working on several projects in Serbia and within the Balkan region. In 2015, she joins EURORDIS as RareConnect Outreach Manager, being responsible for developing and maintaining RareConnect online disease-specific communities encompassing conversations across continents and languages. During the 7 years, RareConnect has grown from dozens to 260 disease-specific communities and became available in 13 languages.

ABOUT MY ORGANISATION:

Sandra has joined CML AN in 2022 as an Online Academy Manager to establish an e-learning platform program (CMLAN Academy) aiming to provide e-courses that are relevant to the CML current and new patient advocates to support them in their advocacy efforts in improving the quality of life of people affected by CML across the world. The Online Academy initiative has spread to meet the e-learning needs of CLL AN and ALAN networks, which is currently growing into - Leukemia Patient Advocates Academy.

CML
HORIZONS
HYBRID MEETING 2024

Your Steering Committee

& Special Advisors

For full Who is Who profiles visit link:
https://cmlhz.cme-congresses.com/
(Door "Who is Who)

or scan the code:

Bahija Gouimi

A.M.A.L. Association

Morocco

How to contact me:

bahijagouimi@gmail.com
2022daralamal@gmail.com
linkedin.com/in/bahija-gouimi-50936785
facebook.com/bahija.gouimi
instagram.com/association_amal/

Catherine Moura

Brazilian Lymphoma and Leukemia Association - ABRALE

Brazil

How to contact me:

Linkedin: http://www.linkedin.com/in/catherinemoura
catherine.moura@abrale.org.br
www.abrale.org.br
+55 (11) 91307-1174

Eunice Orekha

MaxCare Nigeria

Nigeria

How to contact me:

Tel: +234 803 788 0111
Email: maxcarenigeria@yahoo.com
Twitter: @maxcareng
Facebook: Maxcare Nigeria

MY WORK SUPPORTING PATIONTS:

My life took an unexpected turn in 2002 when I was diagnosed with CML while pregnant with my third child. At that time, the lack of treatment, monitoring and psychological support in Morocco intensified the challenges I faced.

Through the establishment of the AMAL Association, writing four books in 2 languages, and sharing my personal story, I aim to inspire and support my community.

AMAL is The first CML patient organization in Morocco & North Africa, founded in April,16th, 2011 in Marrakech to improve access to CML treatment and correct monitoring, education, support of patients and caregivers and advocating to improve policies and decisions in favor of cancer patients.

Recognizing the need for additional support, we built "Dar Al Amal", inaugurated in the World CML Day 2022, a facility providing an accommodation, transportation & assistance to leukemia & cancer patients of Mohamed 6 hospital in Marrakech.

The facility prioritizes patients & parents who face geographic distance from the hospital, financial constraints preventing accommodation payments, the need for continuous medical supervision, and the lack of psychological support.

MY STORY:

MD, MPH, MSc, PX Leader, Health Executive | Caregiver | Believer and Enthusiastic about Public Health, Social Justice |Global Cancer Patient Advocate | Host of the Health and Cancer Policy Podcast | CEO at the Brazilian Lymphoma and Leukemia Association - ABRALE / Brazilian Thalassemia Association – ABRASTA | CML Advocates Network Steering Committee Member and several other coalitions.

ABOUT MY ORGANISATION:

100% effort where there is a 1% chance

Our mission is "Offer help and mobilize partners so that all people with blood cancer in Brazil have access to the best treatment."

Abrale is a nationwide non-profit organization, created in 2002 by patients and family members with the mission of offering help and mobilizing partners so that all people with cancer and blood diseases have access to the best treatment.

Our pillars of action are - patient support, education and information, public policies and advocacy, research and monitoring, with the aim of promoting impact on public health and social impact.

Since our founding, we have helped more than 60,000 patients across the country. Guided by our values, we work to improve access to diagnosis, treatment and quality of life for people with cancer and blood diseases. Abrale is headquartered in São Paulo, with 70 employees and 250 volunteers working in different areas.

MY STORY:

The diagnosis of CML in 2006 was very devastating for my family and I. As a young mother of a one year old son, I thought I wouldn't live long to watch him grow up. My diagnosis was made at the accelerated phase of the disease and the healthcare system in Nigeria did not provide for TKIs. However, through The Max Foundation's Max Access Solutions, I've had access to proper treatment and 17 years on, I am now a Patient Advocate and a Regional Representative desirous of seeing more patients have access to proper treatment

ABOUT MY ORGANISATION:

MaxCare Nigeria is a CML support and advocacy group formed by patients who have CML and GIST in Nigeria. As a group, we strive to provide support (emotional and health-advice) to patients living with CML, equip them with knowledge about the disease, advocate for regular monitoring of their treatment and make necessary intervention with stakeholders when challenges arise in accessing proper treatment.

Our group, informally started March 2011 and obtained official registration in June 2014. Currently, we access Glivec, Tasigna, Bosulif and Sprycel courtesy of generation donation of Pharma companies in collaboration with The Max Foundation through the Max Access Solutions (MAS)

Our activities include:

Provision of peer support to new and old patients and their caregivers

Provision of useful information on the disease to new patients and educating patients on proper disease management through adherence and monitoring.

Advocate for rights and welfare of group members.

Soliciting the help of relevant stakeholders in Nigeria to the challenges of proper access to treatment faced by CML patients

Gerald Clements

CML Buster Foundation

USA

How to contact me:

Cell/WhatsApp +1 714-393-9399
Web: www.CMLBF.org
Email: jerry@CMLBF.org or CFO@CMLBF.org
Facebook: /CMLBusters
LinkdIn: https://www.linkedin.com/company/CMLBF

MY STORY:

Since 2001, with my wife's diagnosis of CML, I have volunteered my time, fortune, talents and passion to improving CML treatments, monitoring and most important emotional support for the daily struggles of those families dealing with this chronic cancer. I have studied, learned, about CML patient's unique needs for over 23 years and continue daily in this effort. I am committed to improving the lives of CML families and to finding a durable cure for CML.

ABOUT MY ORGANISATION:

As of 2023, it is estimated that there are more than 125,000 CML patients and 500,000 CML caregivers in the U.S. The CMLBF goal is to provide them access to CML quality treatment, education and to support services.

In 2003, out of the need for CML knowledge and experience for a new type of cancer treatment, my wife Joannie with another CML patient founded the first U.S. face-to-face CML-specific family support group (FSG). Their mission to "Provide the tools needed for empowerment of CML patients and their families to improve their quality of life."

Since 2003, I have focused my efforts through CML Busters as a CML advocate and caregiver to engage with CML stakeholders on behalf of the U.S. CML community. With the help of our core FSG members, we are a united family providing positive examples of living successfully with CML.

Originally drawing only from Southern California, CML Busters has grown into a powerful network of dedicated members. Utilizing the human connection as a major coping tool, we continue to give each other support, hope, help, and inspiration as we execute our mission and CMLBFFSGs now spans all five U.S. time zones.

In 2019, CML Buster Foundation, was incorporated as a 501(c)(3) NPO to fund our vision of reaching all U.S. patient families. We continue to launch additional family support groups and initiatives to execute on our mission to support our population and to ignite funding for research towards a CML Cure and now serve as the corporate CFO. I am active with the iCMLf, NCCN, Kaiser, FDA, NCI and Pharma as a CML Patient/Caregiver Expert and advisor on the patient perspectives on CML maters.

Over the past 7 years, I have expanded my outreach into international advocacy through CMLAN and serve as the North American Region representative on the Steering Committee, as the CMLAN Treasurer and as the CML-CAB Co-Chair.

We laugh together, we cry together, we are there for each other. We are: #CMLBusterStrong.

Giora Sharf

CML Advocates Network
Flute of Light Patients Organization
Israeli CML Patients Organization

Israel

How to contact me:

Mobile- +972-507516690
gioras@partner.net.il

MY STORY:

I feel that my personal story reflects on the revolution that CML has gone through in the last 20+ years. I was diagnosed with cml at March 2000. Through the internet I found about the opening of the IRIS clinical trial and joined it in July 2000 with Prof Andreas Hochhaus, in Germany. I was randomized to interferon+ara c and took it for 7 months, with terrible side effects. I was switched to 400 mg Glivec which I took daily for 13 years and reached MR5. In June 2014 I have stopped treatment have been on TFR keeping my deep molecular response. Let's hope we can all reach a cure!

ABOUT MY ORGANISATION

I decided to use my experience to help other CML patients and founded the Israeli CML Patient's Organisation in April 2001 with 7 local patients at a small hospital in the city of Netanya, Israel. It has since grown to support more than 580 patients from around the country.

In 2014 I decided to expand our activities to all other blood cancers patients in Israel, and started the Israeli Leukemia and Lymphoma patients Organization named in Hebrew- "Flute of Light". We support all blood cancer patients from all over the country. Our activities are concentrated on patients education, achieving it by holding many patients meetings, writing patients and carers booklets, making videos on each disease and treatments.

We are also involved in other activities like getting needed drugs approved for patients, lobbying at the parliament, field tours of labs and more.

In addition I am one of the co-founders of The Leukemia Patient Advocates Foundation, that hosts the CML Advocates Network, the Acute Leukemia Advocates Network (ALAN), the CLL Advocates Network, the MPN Advocates Network and the CML Horizons meeting.

I am involved in the Steering Committees of the CML and MPN Advocates Network.

Two Years ago I was awarded together with Jan Geissler, the ICMLF award for supporting CML patients all over the world.

Jan Geissler

LeukaNET, Leukemia Patient Advocates Foundation, ALAN, CMLAN, WECAN

Germany

How to contact me:

jan@lepaf.org
Twitter: @jangeissler
LinkedIn: linkedin.com/in/jangeissler/
Facebook: www.fb.me/jangeissler

MY STORY:

I was diagnosed with CML in 2001 at the age of 28. Because Imatinib was not yet approved, I joined a Phase I/II clinical trial combining Imatinib with Peg-Interferon. I have been in stable molecular remission for some years before I stopped Imatinib in 2006 and continued with Peg-Interferon only. In 2014, I stopped all CML therapy in deep molecular response. The CML is sometimes still measurable at a very low level. I have been engaged in patient advocacy since 2002. Outside of CML advocacy, I have mainly focused on capacity building of patient organisations, influencing EU health policy, and driving patient engagement in medicines research & development.

ABOUT MY ORGANISATION:

Leukämie-Online www.leuka.net, launched in 2002, is one of the most frequented online communities for patient and families affected by leukemia, mainly adult and pediatric CML, CLL and AML. The platform provides support to patients by reporting news from research in leukemia. It works closely with hematologists, e.g. in the German CML Alliance and German CML Study Group. LeukaNET is also involved in the HARMONY Alliance, the EU big data project in hematology, www.harmony-alliance.eu The Leukemia Patient Advocates Foundation, co-founded by Giora, Jana, Erik and me in 2011, hosts the CML Advocates Network, the Acute Leukemia Advocates Network (ALAN), the CLL Advocates Network, the MPN Advocates Network. I am involved in the Steering Committees of the CML Advocates Network and ALAN, www.lepaf.org . From 2012-2017, I coordinated the project European Patients' Academy (EUPATI). EUPATI launched its EUPATI Patient Experts Training Course in 2014 and was set up as a non-profit foundation in 2018, www.eupati.eu. I am past chair and coordination team member of WECAN, the workgroup of the 22 pan-European cancer patient orgaisations, www.wecanadvocate.eu . I am also patient representative in the patient advocacy committees of the European Hematology Association (EHA) and the European Cancer Organisation. I am on the board of Patient-Focused Medicines Development (PFMD) and the strategy board of the German National Decade Against Cancer hosted by the German Ministry of Education and Research. I am also founder and CEO of Patvocates, a patient-led think-tank and consultancy on patient advocacy, patient involvement and research, www.patvocates.net

Jana Pelouchova

Diagnoza leukemie, z.s.

Czech Republic

How to contact me:

www.diagnoza-leukemie.cz
facebook.com/diagnoza.leukemie
jana.pelouchova@diagnozaleukemie.cz

non-stop telephone line Jana Pelouchova:

+420 728308360

Jelena Čugurović

CML Association of Serbia

Serbia

How to contact me:

Jcugurovic@gmail.com
cml@cml.rs
+381 64 66 88 174

Nigel Deekes

CML UK - United Kingdom

CML advocates network Steering committee Western Europe representative - 2024

United Kingdom

How to contact me:

ndeekes@gmail.com
0044 7973 509480

MY STORY:

3rd line CML patient since 2002 with Trisomy 8 in Ph-neg. mitotic cells.

Due to challenging history having a strong motivation for patient advocacy both at national level(founder and chair of Diagnoza leukemie) and internationally: LePAF, SC member of both CMLAN and CLLAN, active member of ALAN and MPNAN, MDS Alliance. Member of Ethics Committee and Patient Panel member of the IMI consortium Immune-Image. Member of EHA PAC, member of CAR-T Conference SC and member of ESMO Patient Advocacy Working Group. Involvement with European Medical Agency and EAPM.

ABOUT MY ORGANISATION:

Diagnoza leukemie is a patient-governed society providing education to patients with chronic and acute leukemias, myelodysplastic syndrome and, myeloproliferative neoplasms. Extending its policy and advocacy activities from CML-based community established 2006 into a broader scope of blood cancers (since 2014).

Independent source of disease-related information, platform for patients' networking, improving collaboration with key opinion leaders in each cancer area and implementing best practices and resources from international collaboration (all global patient networks at Leukemia Patient Advocates Foundation).

Chairperson Jana Pelouchova is a member of the Patient Council at the Health Insurance Agency and involved with the drug regulatory body. Member of the Access to Care and eHealth working groups at the Ministry of Health.

MY STORY

My mother was a CML patient. Living with the strongest woman I`ve ever met and her need to help others made me aware of the fact that people with CML needed help in their work. So, I decided to join them and help them in their work.

Today I am SC member and a person responsible for international cooperation in CML Association of Serbia and an active CML advocate for more than 10 years. My work is devoted to helping people with CML by providing them best therapies, good quality of life and focusing on cure both on local and international level.

During my work I have met many great people and friends.

ABOUT MY ORGANISATION:

CML Association of Serbia is committed to bringing the most up-to-date CML information to people with CML, their family members and caregivers. Activities of the Association include improving patients rights with all stakeholders, sharing information on the website and within the chat groups, printing booklets about CML, having professional consultants to answer the patients` questions on the website, organising meetings with the members, helping patients in everyday life, etc.

CML Association of Serbia has more than 280 members and is very active in fighting for patients rights and improving their quality of life.

MY STORY:

Diagnosed in 2011 at 45, I was placed onto Imatinab, I responding relatively slowly to treatment, with no side effects.

In March 2015 I was offered a place on the DESTINY trial in the UK, where the dose was reduced for 12 months by half, with monthly PCR's, I then stopped treatment. Very quickly my levels rose and so I was back on full dose responding well.

In Nov 2021 I went onto half dose, and Nov 22 TFR for my second attempt. My last PCR in March 2024 was excellent, giving me my second only undetectable in 13 years.

WHY I AM A CML-CAB MEMBER:

I am a passionate, patient advocate wanting to give help, and advice to fellow CML patients. I founded CML UK, a Facebook group, back in 2012, we now have 4500 members in the UK and worldwide. Additionally I am also a moderator on CML worldwide, where we have approximately 7000 members.

Our Facebook group is a closed group so only members are able to see and respond to comments. This is something that was wanted as feeds were going out to members own personal pages and so being seen by anyone, some patients do not of course, wish their family or friends to know of their illness. Within a closed group, members can be frank amongst fellow CMLer's.

CML UK was set up to enable patients and carers to come together and share experiences, advice and knowledge. These two groups are very helpful, particularly to those that have been recently diagnosed.

I firmly believe we all have to work together to give all avenues of help to patients and so thank other groups and members here for all you do.

Patricia Garcia-Gonzalez

The Max Foundation

USA

How to contact me:

pato@themaxfoundation.org

MY STORY:

For more than 20 years, Pat Garcia-Gonzalez, has been dedicated to improving the lives of cancer survivors around the world. A native of Argentina, Pat has a master's degree from the University of Washington and a technical degree in nursing.

Pat is the co-founder of The Max Foundation, established in 1997 in honor of her step-son, Max. Max was diagnosed with chronic myeloid leukemia (CML) at the age of 14. He survived until the age of 17, and his legacy lives on in the hearts of thousands of cancer survivors whose lives have been touched by the organization.

Roderick Padua

TOUCHED BY MAX (TBM), INC.

Philippines

How to contact me:

rod_padua@yahoo.com
+639088734617 (watsapp, viber, Linkedin)

MY STORY:

My son, Maverick had CML when he was 9 years old. He is now 26. He has served as my inspiration in "giving back" to the community through my advocacy efforts and interventions. I am President of TBM for the last 17 years. I am a Steering Committee member (Asia-Pacific elected) of the CML Advocates Network and concurrently the Chair of the SC. I am also a member of the CML Community Advisory Board. Lately, in 2021 I was made a Council member and Strategic Advisor for the Alliance & Partnerships for Patient Innovation and Solutions (APPIS).

ABOUT MY ORGANISATION:

I have been attending CML Horizons for the last 13 years (it was then called New Horizons in 2010) and has served me excellently in my advocacy efforts in the Philippines. Touched By Max, Inc. started with 20 patients in 2003 and has since grown to over 2,200 members in all these years. We conduct medical sessions on CML regarding the latest updates regarding therapies, research, QoL, comorbidities, TFR and other pertinent issues that are equally important to our members. Because of our partnerships locally and internationally, we are able to source assistances and grants that TBM in turn facilitate, to make the lives of our members as normal as possible. Depending on the current "noise" needed to make an impact, we initiate the appropriate awareness campaign to drive home a point. Being a member of the Cancer Coalition of the Philippines, our latest success was the realization of the National Cancer Control Law, which will spur much-needed benefits to CML patients.

For full Who is Who profiles visit link:
https://cmlhz.cme-congresses.com/
(Door “Who is Who)

or scan the code:

Speakers

Andreas Hochhaus

Jena University Hospital

German CML Alliance

President, German Society of Hematology and Medical Oncology

Germany

How to contact me:

andreas.hochhaus@med.uni-jena.de
#hochhaus66,
@AndreasHochhaus
+49 3641 932 4201

Dr. Amma Benneh-Akwasi Kuma

Department of Haematology University of Ghana Medical School /
Korle- Bu Teaching Hospital

Ghana

How to contact me:

animabenneh@yahoo. com

Daniela Žáčková, MD, PhD

University Hospital Brno,

Czech Republic

How to contact me:

E-mail: zackova.daniela@fnbrno.cz;
X: @Danielakov2
LinkedIn, Facebook

MY WORK SUPPORTING PATIENTS

Coordination of national and international clinical trials.

Providing infrastructure for cooperation between patient advocates and CML treatment sites.

MY WORK SUPPORTING PATIENTS

It's been a worthwhile experience as a Hematologist managing patients living with various haematological disorders for more than 22 years. However, for more than 17 years managing patients with Chronic Myeloid Leukaemia (CML) has been my passion , pride and joy. Establishing a dedicated weekly CML clinic at our centre has significantly enhanced the monitoring and care of patients living with CML.

Diagnosis and monitoring of patients living with CML at our centre has also been greatly enhanced with the provision of a Cepheid GeneXpert system This has made molecular testing more affordable and coupled with a shorter turnaround time early diagnosis is possible and better treatment outcomes have been achieved.

Bonds of friendship have been fostered, experiences and words of encouragement shared with the formation of CMLAG; CML support group. Programs aimed at creating awareness among the populace on CML have also been organized. All this would not have been possible without Novartis, Max Foundation, international chronic myeloid leukaemia foundation (iCMLf),Cepheid, Bristol-Myers Squibb, Pfizer and Ariad. Thank you all very much for your continuous dedication and support. Kudos to all the Doctors and Nurses of the Department of Haematology, Korle-Bu Teaching Hospital, Accra, Ghana for together as a team we help make the lives of people living with CML a better one.

MY WORK SUPPORTING PATIENTS

I am Consultant in Hematology and Associate Professor at the Department of Internal Medicine, Hematology and Oncology, University Hospital Brno and Masaryk University, Brno, Czech Republic. My clinical and scientific interests are mainly focused on chronic myeloid leukemia (CML). This led me not only to become the head of the CML working group at our institution, but also to serve as the national coordinator of international projects and trials such as CML IV study, TIGER (CML V) study, EURO-SKI/AFTER-SKI, PONDEROSA, and Blast Crisis Registry. I act as the expert guarantor of the Czech Registry of CML patients, named INFINITY, and as the principal investigator of the nationwide, investigator-initiated phase II trial HALF, which tests the efficacy and safety of tyrosine kinase inhibitor (TKI) therapy discontinuation after a two-step dose reduction.

I am a member of the European Hematology Association (EHA), the European LeukemiaNet (ELN), the CzEch Leukemia Study Group – for Life (CELL) and have been the elected Chair of the Audit Committee of the Czech Hematology Association since 2022 (an elected member since 2018). I have authored or co-authored more than 90 peer-reviewed articles, and several scholarly books, textbooks, or textbook chapters, including a comprehensive brochure for CML patients and their relatives.

Since 2007, I have collaborated with the patient supportive organisation "Diagnóza leukemie" (originally "Diagnóza CML"), led by very active patient advocate and co-founder of the CML Advocates Network, Jana Pelouchová. I am not only a member of the Advisory Board but also actively participate in annual patients' meetings and in the videorecording of lectures and interviews published on the organisation's websites. I participated as a speaker at CML Horizons Conference 2016 in Ljubljana, Slovenija.
I was also involved in the global educational campaign called "What If? What Now?", which resulted in a video interview titled "Understanding Your Diagnosis" with Nigel Deekes, a member of the CML Steering Committee of the CML Advocates Network. This effort also included a unique joint patient-physician perspective on treatment-free remission (TFR), published as a scientific paper (Saglio G., et al., 2018). In 2021, I participated together with Jana Pelouchová in the virtual "Patients today" activity focused on highlights presented during ESMO 2021.

Irene Caballes

Clinical Nurse Specialist

Imperial College Healthcare NHS Trust
Hammersmith Hospital

United Kingdom

How to contact me:

Email: Irene.caballes@nhs.net
X(Twitter) @i_caballes

Jorge Cortes

Georgia Cancer Center

Augusta, Georgia,

USA

How to contact me:

jorge.cortes@augusta.edu
@GCC_Cortes

Liat Rotem Melamed

Israel

How to contact me:

058-5559082

MY WORK SUPPORTING PATIENTS

I have extensive nursing experience caring for patients with blood cancers. Haematology nursing has always been my passion. I have been a haematology clinical nurse specialist (CNS) since 2012 at Imperial College Healthcare NHS Trust Hammersmith Hospital London United Kingdom considered as a highly reputable centre of excellence for blood cancers. I am privileged to provide holistic nurse specialist support to patients with Chronic Myeloid Leukaemia (CML) and provide invaluable attention to patients and their families in managing their long-term side effects, medication adherence and compliance; promotes discussion about patient's symptoms, psychological and social aspects of care and assist them in achieving improved quality of life. An established virtual CML patient/carer support group meeting is accessible to our patients as an additional resource to acquire better understanding of their condition, find strength and support from one another. I manage a nurse-led clinics for suitable stable CML patients who require monitoring treatment response, review and prescribe continuous patient medications and arrange follow-ups within safe practice guidelines. I am committed to a collaborative multidisciplinary working relationship to overcome the challenges in delivering quality, safe patient care and achieve the best possible patient experience and treatment outcome.

MY WORK SUPPORTING PATIENTS

I have been involved with CML research for over 20 years. I participated in the initial trials with STI-571 (now imatinib, Gleevec, Glivec), and have participated in multiple clinical trials with all available drugs and many other investigational approaches for CML. I was the lead investigator in trials of three drugs that have been approved for CML in various parts of the world: bosutinib, ponatinib and omacetaxine. I have a very extensive CML clinic with patients from all over the world. I am one of the founding members and the current Chair of the International CML Foundation, and the chair of the John Goldman ESH/iCMLf Annual Conference on Chronic Myeloid Leukemia: Biology and Therapy.

MY WORK SUPPORTING PATIENTS

- Expert in the patient journey in the digital world
- Strong believer in patient empowerment to achieve better recovery and health outcomes.
- Co-founder and leader of "The First School in Israel for Healthy Communities" with "Habridiyot", aiming to train organizations and health community leaders in Israel.
- Founder and leader of the Israeli branch of the global Coalition Next initiative, which aims to implement innovation in healthcare organizations within the framework of local ecosystem collaboration.
- Host of two healthcare podcasts (in Hebrew): "Participatient", which focuses on patient empowerment in the digital age, and "The Patient Behind The StartUp", which focuses on entrepreneurs in the digital health field.
- Member of the lecturer team of the "Israeli Marketing Association"
- Manager of the "Women of the United Health World" Facebook community, which has over 2,000 women and aims to promote women to senior management positions in the healthcare system.

Paula Florencia Capparelli

European Patient Advocacy Institute

Spain

How to contact me:

Email: paula@patientadvocacy.eu
www.linkedin.com/in/paulacapparelli/

Richard Van Etten, MD, PhD

University of California,
Irvine Chao Family Comprehensive Cancer Center

United States

How to contact me:

Email: vanetten@hs.uci.edu

LinkedIn:
www.linkedin.com/in/rick-van-etten-5316b533/

Roi Shternin

Patient Pioneer

Chronically: A Movement Transforming Patient-Centered Healthcare

Austria / Israel

How to contact me:

My Linkedin is the best way to reach me:
https://www.linkedin.com/in/roishternin/
roi@shternin.com

MY WORK SUPPORTING PATIENTS

The European Patient Advocacy Institute (EPAI) is a charitable institution founded in Germany in 2017. Serving as a patient-led education and research platform, EPAI is dedicated to enhancing patient advocacy and involvement. The institute strives to empower the patient community through the development, leadership, and implementation of methodologies, processes, and projects that strengthen patient advocacy, involvement, and evidence generation across patient advocacy, research, health policy, and healthcare services.

EPAI collaborates with patient advocacy organizations and various healthcare stakeholders to instigate change. Our partnerships encompass a diverse range of networks and initiatives committed to patient-centered care.

As a Senior Project Manager at EPAI, I blend my expertise in digital transformation, innovation, and healthcare to drive patient advocacy initiatives forward. With a background in Social Communication, an MBA, and specialized training in entrepreneurship, human-centered design, and digital transformation, I'm an expert at harnessing technology to enhance processes.

Having co-founded a successful magazine and served as CEO of a health-tech startup leveraging Artificial Intelligence, I excel in managing multiple digital tools to innovate within diverse sectors. My 7+ years of experience as head of MarComms for a non-profit entrepreneurship center has given me the skills to develop digital strategies to achieve organizational goals.

Now at EPAI, I'm passionate about sharing insights on digital and AI-driven tools to empower fellow advocates in leveraging technology for effective patient advocacy and care.

MY WORK SUPPORTING PATIENTS

Dr. Richard Van Etten is the Director of the University of California, Irvine Chao Family Comprehensive Cancer Center, 1 of only 57 National Cancer Institute (NCI)-designated Comprehensive Cancer Centers in the United States, located in Orange County, California.

Dr. Van Etten received his MD and PhD in Biophysics from Stanford University School of Medicine. He is a board-certified hematologist specializing in blood cancers – leukemia, myeloma, and lymphoma.

His personal story with CML began as a Visiting Scientist from 1988-1991 in the laboratory of Nobel Laureate Dr. David Baltimore at the Whitehead Institute at MIT, where he and Dr. George Daley developed the first genetically engineered mouse model of CML, proving that the disease was caused directly by the BCR::ABL1 fusion gene and protein.

Since then, his laboratory, funded by the NCI and the Leukemia & Lymphoma Society, has carried out numerous studies to define the critical pathways involved in CML pathogenesis.

Currently at UC Irvine, he and collaborators are focused on the systems biology of CML, using mathematical models of the disease to identify new approaches to treat primary TKI resistance and improve TFR. He is also principal investigator on several clinical trials in CML and other blood cancers.

MY WORK SUPPORTING PATIENTS

About me: I empower patients and build patient-centered systems. Facing illness, I championed my own health journey and now inspire others. As a speaker, author (3 books!), and founder of the Chronically movement, I'm dedicated to transforming healthcare.

Description of Chronically: Chronically isn't just an organization; it's a movement with a heartbeat, pulsing through the veins of the healthcare industry. United by a vision of patient empowerment and healthcare transformation, we're a collective force advocating for change. We believe every voice matters, and every experience shapes the future of care.

Our Thriving Community: We're a tapestry of patients, healthcare professionals, policy influencers, and industry innovators. This vibrant community is the driving force behind our mission – to weave patient perspectives deeply into the fabric of healthcare systems worldwide. Through active dialogue, shared stories, and collaborative efforts, we're not just envisioning a new healthcare paradigm; we're creating it.

Join the Movement: Chronically is more than just a name; it's a commitment to a cause, a dedication to a purpose, and a rallying cry for those who believe in a better healthcare future. Whether you're a CML patient advocate or someone passionate about patient empowerment in any chronic illness, we welcome you to join our movement.

Additional Information: I'm honored to be attending CML Horizons 2024 as a guest speaker on patient empowerment. While Chronically's focus isn't solely on CML, we believe in supporting all chronic illness communities. I'm excited to connect with CML advocates and share insights on empowering patients to navigate their healthcare journey.

S. Tiong Ong, MA, MBBCh, MRCP (UK)

Cancer & Stem Cell Biology Signature Research Programme, Duke-NUS Medical School,
Singapore,

Division of Hematologic Malignancies & Cellular Therapy, Duke University Medical Center, Durham, NC
USA

How to contact me:
Email: paula@patientadvocacy.eu
www.linkedin.com/in/paulacapparelli/

MY WORK SUPPORTING PATIENTS

- I am a practicing hematologist/oncologist who sees patients with CML.
- I also perform research that is directed toward understanding the mechanisms underlying resistance to targeted therapies in blood cancers, including CML.
- By understanding mechanisms of resistance, we can better devise ways to identify patients who are likely to become resistant during their therapy, and also develop new approaches to prevent and/or overcome resistance.

CML HORIZONS
HYBRID MEETING 2024

For full Who is Who profiles visit link:
https://cmlhz.cme-congresses.com/
(Door “Who is Who)

or scan the code:

Delegates

Afi Micheline

NGO Apsbes

Togo

How to contact me:

aspbes_ong@yahoo.fr

Adriana Livia Covaciu

Romanian Association of Rare Cancers-Dorica Dan/ CMLro

Romania

How to contact me:

Adriana.Covaciu@gmail.com
Phone: 0040 769472207

Amihud Carmon

Israeli CML patients organization

Israel

How to contact me:

My mail is: amicar@gmail.com
My phone is: 972-54-8103939
My twitter is: twitter.com/Amicarmon
Facebook: Ami Carmon

MY STORY:

I was diagnosed with CML in 2004, since then my life has totally changed. I'm currently in remission, haven't had treatment for 4 years. Ever since my diagnosis I wanted to get to the point where I could teach other patients how to live with CML, what is good to do in their daily lives, where to get their information, and how to have a healing psyche. In 2011 I was part of a campaign that took place in Romania that aimed to raise awareness of rare cancers. The campaign was called "Adriana exists", and it had a very big impact, because people saw that it is possible to live with a rare cancer, but also the importance of regular monitoring with tests. That was the moment when I started to gather other patients around me and to build a community of CML patients in Romania.

ABOUT MY ORGANISATION:

The Romanian Association of Rare Cancers - ARCrare was founded in June 2011 from the desire to represent people affected by rare cancers in Romania, their families and specialists involved in their diagnosis and treatment.

CMLRO is the future association dedicated to CML patients. By founding it we want to reach, first of all, all CML patients in Romania. To integrate them in support groups, to teach them how to live with a rare disease, to know what rights they have, and to be always informed about the disease they have.

MY STORY:

I was diagnost on 6.2013. I started with 400 mg gleevec but after a year ,because pcr started going up my doctor moved me to spycell, 100 mg a day.

I suffered from Pleural Effusion and had to stop sprycell. Back to gleevec. The side effects bother me but I decided to ignore them and continue my life. after years of suffering from pain, I changed doctors and than stopped Gleevec. The pains all stopped within a day. I am a year on asciminib without any side effects.

ABOUT MY ORGANISATION:

The Israeli CML patients organization was founded in April 2001.

The organization conducts monthly meeting with many different activities on various CML related topics,like, prezentations and lectures by most of CML experts in israel ,etc.

We have a web site www.cml.org.il .

Our organization is involved in other activities like getting needed drugs approved for patients, lobbying at the parliament and more.

Once a year we organize CML awareness weekend with more than 200 patients and caregivers

Andrea Preston

CML UK – Facebook Group

United Kingdom

How to contact me:

Andrea@saniushealth.com

Athanasia Samara

K.E.F.I of Greece

Greece

How to contact me:

samara_ath2012@yahoo.gr
Phone +306932462515
Mobile +306932462515

Aura Coronel

Asociacion de Pacientes y Parientes con Enfermedades Hematologicas

Panamá

How to contact me:

+507 6262-9247
auracoronel@hotmail.com
Auracoronel15 (Instagram)
Aura Coronel (facebook)

MY STORY:

I am a haematology pharmacist based in Bristol and am Head of Patient Innovation and Care at Sanius Health- a patient led health tech company passionate about improving outcomes for patients and accelerating research. I co-created the recently launched MyCML app with fellow pharmacist Nick Duncan, working closely with Nigel Deekes from CML UK and David Fitzgerald from CML Support. I am delighted to be further developing the app with Sanius Health.

ABOUT MY ORGANISATION:

Founded CML UK, a Facebook group, back in 2012, we now have 4500 members in the UK and worldwide. Additionally I am also a moderator on CML worldwide, where we have approximately 6000 members.

Our Facebook group is a closed group so only members are able to see and respond to comments. This is something that was wanted as feeds were going out to members own personal pages and so being seen by anyone, some patients do not of course, wish their family or friends to know of their illness. Within a closed group, members can be frank amongst fellow CMLer's.

CML UK was set up to enable patients and carers to come together and share experiences, advice and knowledge. These two groups are very helpful, particularly to those that have been recently diagnosed.

I firmly believe we all have to work together to give all avenues of help to patients and so thank other groups and members here for all you do.

MY STORY:

I am a Greek high school teacher and I was diagnosed with CML on September 14,2010 .In November 2017 I have stopped my treatment and every 4 months I do PCR tests ,which show that I am in high molecular response .I feel good ,I continue teaching and keep up my year round sea swimming. In Greece there was not a group of CML patients ,so with the support of KEFI,I started a small group trying to help CML friends and newly diagnosed patients.

ABOUT MY ORGANISATION:

K.E.F.I was established in 2004 aiming at providing emotional, psychological and social support to cancer patients and their families ,as well to rase awareness and increase sensitivity in society on issues related to cancer prevention and care

K.E.F.I is run by a board of cancer survivors and volunteers and organizes varieties of seminars and conferences for patients and families ,education on most common and less common cancers ,while its most important program is the training of its volunteers .So far more than 150 volunteers have been trained to provide support to cancer patients in treatment Some 10000 patients and family members have been supported during the 20 years of operation of K.E.F.I

MY STORY:

I found out about the association when my daughter got sick in 2015, I found support not only in the association but also in many other people who suffered from different diseases, my daughter has a rare disease and is the only person in Panama with the disease, The doctors encouraged me to participate in the association and meet more people, I am grateful for the opportunity and I dedicated myself to being part of it, learning, fighting and studying about so many things to be able to help not only my daughter, but also to all people who suffer from something and need help. I am happy being APPPEH, I enjoy learning more every day

ABOUT MY ORGANISATION:

My association is dedicated to helping patients and relatives with all hematological diseases in our country. We fight together to obtain the necessary medicines, we train patients with the help of hematologists so they could learn more about their diseases, not just fisically, emotional support too. We a family that fight together for the health and wellness of each patient and other different assoaciations in our country. Happy to be part of APPPEH

Aurélie Daban

LMC France

France

How to contact me:

mdlmcfrance@gmail.com

Boris Machavariani

The Alliance of CML Patients of Georgia

Georgia

How to contact me:

bmachavariani@gmail.com
Tel: +995 599 217718

Brenda Silvana Hurtado Wills

Celebrando la Vida

Bolivia

How to contact me:

Email: dabrenhw@hotmail.com
Cell: 59170029100

MY STORY:

Aurélie brings her expertise and dedication to LMC France, not only as the vice president but also as a caregiver. Her multifaceted role within the organization contributes significantly to its mission.

Aurélie’s involvement with LMC France goes beyond professional duties; She has been actively supporting the association for several years and is deeply moved by the impact of the disease on individuals and their loved ones.

Aurélie supports the actions of LMC France in various ways, playing a pivotal role in advancing the organization’s goals.

ABOUT MY ORGANISATION:

Established in February 2010, LMC France is the first association of CML patients in France, today counting over 2 500 members. LMC France provides information, resources and support to CML patients and their families.

LMC France aims to develop through all means any actions related to chronic myeloid leukemia (CML). The association also brings together patients and families to assist them in their fight against the disease through research, information and support events.

LMC France is the organizer of various innovative events as well as the creator of the “WORLDWIDE CML DAY». The first event was held, symbolically, on September 22 2011, and was followed all over the world.

With these fundraising events the proceeds are handed over to groups to advance research in the field.

Since 2010, LMC France is a referenced website with information approved by the renowned members of the scientific committee. There is also support for patients and their families with use of social networking and shared spaces, meetings, psychological support, creation of patient tools (eg: LMCoach, the 1st ever e-health continuous coaching service for patients suffering from CML), e learning training: e-university LMC France.

As well as achievements that give hope such as: songs, CDs, photo contests, photo exhibitions, videos and newsletters.

MY STORY:

Without CML – before 11/2012, With CML – after 11/2012

Just made simple ordinary blood test and the doctor which was not hematologist - “You have to visit hematologist because you have very serious blood problem ... after silence ... he says - it can be blood cancer”. During the next days was reading everything about blood WBC, CBC etc. After then hematologist, Philadelphia chromosome positive, WBC, CBC everything about blood and the end was CML, BCR-ABL which becomes my favourite abbreviation in my life.

ABOUT MY ORGANISATION:

Alliance was established in 2013 to consolidate CML patients in Country and improve CML treatment and monitoring tools. The general objective of Alliance are:

To increase of awareness of CML patients and better understanding of disease; To establish a communications between the CML patients, other interested persons (individual, doctor and etc.) and bring them together in “One Family”; To protect CML patients and Alliance member’s right in Georgia; To Support in implementation and organization of CML prevention, diagnostic and treatment measures; To facilitate improvement of quality of CML Patients medical service and insure its availability on a permanent basis; To support of establishment of internationally recognized CML treatment standards, methodology and guidelines in Georgia; Establishment of communications with local governmental bodies and NGO’s, as well as with business sectors interested to support Georgian CML’ers; Divulge information regarding new achievement of CML treatments methodology and issue of leaflets, magazines, booklets, information letters etc.; Creation of learning classis and education activities

MY STORY:

My name is Brenda Hurtado Wills, I am President of the Association for the fight against leukemia “Celebrating Life“ (Celebrando la Vida).

In 2010 I was diagnosed with Chronic Myeloid Leukemia, I was treated with Imatinib 300 mg until December 2022 and until now I am free of treatment and in complete molecular remission.

My life motto in all these years is: “Blessed leukemia that puts me on the right path and with the right people.” Just as it does now.

ABOUT MY ORGANISATION:

“Celebrating Life” is a non-profit organization, made up of people undergoing treatment for Chronic Myeloid Leukemia (CML), Acute Lymphoblastic Leukemia (ALL) and Gastrointestinal Stromal Tumor (Gist), from the city of Santa Cruz de the Sierra, Bolivia.

We currently have 155 patients and our main objective is to work in their defense, in collaboration with local and national authorities, such as the Ministry of Health, the Network Directorate and the National Program to Fight Cancer to achieve a better standard of living. for all.

Cornelia Garnitz

LeukaNet e.V.

Germany

How to contact me:

E-Mail: cornelia_garnitz@t-online.de
Mobile: +49 162 9475321

MY STORY:

Since 2013, my twelve years old son was diagnosed with CML, I became an active member of LeukaNet. Not least because I attended numerous medical events, I gained well-founded knowledge in CML. I need this acquired learnings to feel save and give the best support to my son and other CML patients. My son Yunus is now 23 years old and a CML patient for about 11 years. He was treating with Sprycel (Dasatinib), but his TFR faild and he recently switched to Asciminib (Scemblix).

This is my 10th participation at CML Horizon

ABOUT MY ORGANISATION:

LeukaNET e.V. / Leukämie Online is one of the most frequented communities for leukaemia patients in German-speaking countries. This web-based network provides support to patients by translating and reporting news about new research publications and various treatment options for leukaemia. Leukämie-Online was launched in 2002. Every year, there are approximately 20 children under the age of 18 who are newly diagnosed with CML in Germany.

My reponsibility is to represent the interests of families with children living with CML under the umbrella of LeukaNet: organize meetings for parents, implement events for children and their siblings, organize online meetings.

LeukaNet e.V. works closely with hematologists, e.g. in the German CML Allianz and the CML Advocates Network

Damian Gabilondo

ALMA

Argentina

How to contact me:

@damiangabilondo
Phone: +54-113-540-9601
damiangabilondo@gmail.com

MY STORY:

Having a 42 year old wife and two daughters, i was diagnosed in march 2018. In may 2018 i started my treatment with nilotinib 600 daily, i achieved rm.4.0 In 1 year. After maintaining deep mri for 4 years in january 2023, the medication discontinuation protocol (tfr) start following today's day in tfr

ABOUT MY ORGANISATION:

ALMA is made up of patients and relatives of patients diagnosed with Chronic Myeloid Leukemia (CML).We seek from our experience and experience to be able to contain and help other patients.Our board of directors is made up of patients Our mission: Provide emotional and practical support to patients with leukemia and other blood diseases not supported by other patient organizations.

Our vision: To be the reference patient support organization, providing quality work, meeting the needs of our beneficiaries, the patients.

David FitzGerald

CML Support

United Kingdom

How to contact me:

Email: david@fitzg.com
Phone: +44 7779 030165

MY STORY:

Presenting with retinal hemorrhage, I was diagnosed with CML in November 2012.

I was placed on the imatinib arm of the SPIRIT 2 trial, only to develop difficult to manage musculoskeletal side-effects. Due to this, I was placed on dasatinib in February 2013 and am doing well, achieving MMR in late 2014 and very recently MR4.5 on a reduced dose of dasatinib. I'm hopin

ABOUT MY ORGANISATION:

Originally established in 1999 by two patients diagnosed with PH+ CML, the website was launched in April 2000 in order to reach a wider community of patients diagnosed with CML in order to provide support, advice and up to date information about the disease and its treatment options. We are the UK's only charity with an exclusive focus on people diagnosed with Ph+ Chronic Myeloid Leukaemia. Part of our support is on the psycho/social issues of patient experience, a provision that is often lacking given the requirement for health professionals to address the complex clinical aspects of CML. We therefore see our role as an essential supplement to good professional health care. We also represent UK CML patients during drug reimbursement appraisals at national, government-sponsored meetings as well as in all matters affecting treatment options that originate from the EU and its institutions. The CML Support Group takes an active role in a wide range of consultative bodies throughout the NHS.

Dražen Vincek

HULL

Croatia

How to contact me:

dvincek.hull@gmail.com
udruga.hull.zagreb@gmail.com

MY STORY:

My name is Dražen Vincek and I am a retired criminologist and expert specialist in criminology, who worked all of his life as a police officer in the Ministry of Interior Affairs and as an active member of the Ministry of Defense. I was diagnosed with type 2 diabetes 20 years ago and then I was diagnosed with chronic myeloid leukemia (CML) in 2010. I learned to live with my diagnosis and I try to make the most of every day. As I realised that I am able to share my story with others, I became a member of The Croatian Leukemia and Lymphoma society and then afterwards a President of the said organization.As for my diagnosis, my results are still good and my illness is in remission.

ABOUT MY ORGANISATION:

The Croatian Leukemia and Lymphoma society is an association of patients founded in 1994. at the initiative of our leading hematologists. We are a volunteer and non-profit organization that brings together patients with malignant hematological diseases, relatives and health professionals. We inform patients, connect them with those who have undergone treatments,transplants and provide psychological support. Once you discover that you are ill it is important to be well informed. There is a common opinion that hematological diseases are lethal which is not always true and patients should be well informed about all the possibilities of their cure. Our main branch is in Zagreb and we also have branches in four other cities across Croatia (Donji Miholjac, Slavonski Brod, Varaždin and Zadar). We are members of different european and international organisations who provide informations about hematological diseases.

Dunique Renee Yuill

The Leukemia & Lymphoma Society

USA

How to contact me:

Nikki.Yuill@lls.org
914-821-8275

MY STORY:

I work with patients, families and health professionals to assure access to accurate and up to date disease information, treatment options, connect with psychosocial support, and connect patients to clinical trials, through our LLS personalized Clinical Trial Support Center. We provide comprehensive support services to patients and families throughout the entire blood cancer journey.

On a personal note, I lost my grandmother to CML in 1996, just before the revolution of TKI's and Gleevec/Imatinib became available in clinical trials.

ABOUT MY ORGANISATION:

My Organization: The LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services.

LLS exists to find cures and improve the quality of life of blood cancer patients and their families.LLS is the leading source of free blood cancer information, education and support. LLS funds research to advance more breakthrough therapies for blood cancer patients. LLS is the voice for all blood cancer patients, driving policies that accelerate the development and approval of new treatments and ensure access to quality care. LLS is proud to be playing a major role in the fight again leukemia, lymphoma, and myeloma as the leading private funder of blood cancer research and support programs for patients and their families.

Ebna Habib Sohag Rahaman

Bangladesh CML Support Group

Bangladesh

How to contact me:

Email: sohag72@gmail.com
Phone: +8801711070559
https://www.facebook.com/groups/245872278908865

MY STORY:

I was a post graduated student when I diagnosed CML in 2002. Since then, I'm taking Glivec 400mg with the support from The Max Foundation and Novartis. I got married in 2006, blessed with a beautiful daughter and son. Now I am leading very happy life with my family, don't have feeling that I am sick... helping people to reduce stigma and encouraging them to fight against "Big C". I feel proud to work for the CML community in Bangladesh.

ABOUT MY ORGANISATION:

Bangladesh CML Support Group was formed in 2013 with a mission to support the CML affected community in Bangladesh. Initially we have started with 3 CML survivors now we are 100 plus in numbers. We have been in action since 2013 in full phase in touch of The Max Foundation. We are now a global partner of the Max Global Network and CML Advocates Network. We are a group based in Dhaka, Bangladesh. Our vision is a world where all people facing CML, live with dignity and hope. Our group has been providing much into mental support to the affected & their caregivers, create awareness and reduce stigma on CML. Creating network among the community is also one of our moto. We are struggling to support our patients in access to treatment and monitoring of disease among the CML community in Bangladesh.

Eija Saario

Association of Cancer Patients in Finland

Finland

How to contact me:

eijasaario6@gmail.com

MY STORY:

I am 71 years old and am living in Helsinki with my husband. I worked in communications as a director. I was diagnosed with CML last year. I have received good care at Helsinki University Hospital's Cancer Clinic. I was previously diagnosed with breast cancer and it was successfully treated.

ABOUT MY ORGANISATION:

The aim of the Association is to safeguard the best possible support for cancer patients and their loved ones during treatment and rehabilitation. The Association is active in patient advocacy and involved in national HTA processes

Emma Andersson

Association of
Cancer Patients in Finland

Finland

How to contact me:

emma.andersson@syopapotilaat.fiwww.
linkedin.com/in/emma-andersson/

MY STORY:

I've been working as an Advocacy Specialist at the Association of Cancer Patients in Finland since 2017. I'm involved e.g. in the national HTA process, I draft statements and work with national and international stakeholders. I also cover Survivorship topics (incl. Cancer & Work) and work as a focal point for our international cooperation. I hold a Master's degree in both Political Science and German literature and culture at the University of Helsinki in Finland.

ABOUT MY ORGANISATION:

The Association of Cancer Patients in Finland works to safeguard the best possible support for adult cancer patients and their loved ones during treatment, rehabilitation and any other life circumstances after one's cancer diagnosis.

The Association is active in patient advocacy and involved in national HTA processes, offers peer support as well as evidence-based information for patients and professionals meeting patients in their professional capacity.

The Association moderates 31 cancer-specific or thematic closed Facebook groups. The Finnish CML Patient Network has currently 271 members. Check out for more at www.syopapotilaat.fi/en/frontpage-2/ and www.facebook.com/cancerpatientsFinland.

The Association of Cancer Patients in Finland was established in 1971 and is a member of the Cancer Society of Finland.

Evan Ole Mapelu

HENZO Kenya

Kenya

How to contact me:

email: omapelu@gmail.com,
chairman@henzokenya.or.ke
Phone +254722242766
Facebook: Elo Mapelu
LinkedIn: Elo Mapelu
Twitter: @elo_mapelu

MY STORY:

Iam a passionate advocate and leader, committed to efforts towards winning the war on CML and Cancer in general. Iam one of the founding members of Henzo Kenya, a group that was formed to address various issues relating to CML and Gist patients who were recipients of medications support from the GIPAP program (Now MAS) I have worked with the group since its inception todate. I have held various positions, including chairman, since 2018.

I am also currently chairing the Board of directors of the umbrella organization (Kenyan Network of Cancer Organizations – KENCO), having been elected in August 2022

ABOUT MY ORGANISATION:

HENZO KENYA, is a Community Based Organization Registered in 2008 in Kenya. It brings together Chronic Myeloid Leukemia (CML) and Gastro-intestinal stromal tumors (GIST) patients, a community of about 1500 now, from all over the country. Majority of these patients are CML patients who are currently more than 1,100. Our Mission is to create awareness about CML and GIST, provide emotional and social support to members and other cancer patients and to advocate for mainstreaming of issues related to these cancers that affect patients and general public. Our Vision to be the hub of information, psycho social and emotional support for CML and GIST patients and a key advocate for the same. www.henzokenya.or.ke

Faustina Díaz de López

Panamanian Association of Patients and Relatives with Hematological Diseases (APPPEH)

Panamá

How to contact me:

Email: fdiazq@hotmail.com, fdiazq10@gmail.com
Facebook: Faustina diaz quiroz
Instagram: fdiazq10
Twitter: @fdiazq1

MY STORY:

Graduate in Sociology. Currently retired, but I work in a state institution, as head of the Office of Equalization of Opportunities and Gender. I am dedicated to caring for and training people in the different areas of my responsibilities. If you suffer harassment at work, or violence and people with disabilities, I am the outgoing President, I will soon assume the position of vice president of the Panamanian Association of Patients and Families with Hematological Diseases (APPPEH), also vice president of the Board of Directors of the National Federation of Associations of Chronic Critical and Degenerative Diseases (FENAECCD), I represent her as a commissioner on the High Level Commission for the Improvement of the Public Health System of Panama and on the Board of Directors of the Board of Trustees of the National Blood Center, as a member.

We have been training in different areas, Word, Excel, the 4 levels, Power Point, Diploma in Communication University of Panama, we have actively participated in Advocacy activities, in the Assembly of Deputies, ensuring that the laws they discuss regarding health , our proposals are included.

ABOUT MY ORGANISATION:

A non-profit association that was born in 2005, due to the concern of a group of patients and relatives concerned about the growth of the population of patients with hematological diseases, due to the lack of medicines and physical space of the Hematology Room of the Social Security Fund which was very small and exposed to many bacteria and microbes y the Outpatient Chemotherapy room in the Social Security Fund and with the dream of creating a Bone Marrow Transplant room.

In 2010 it obtained its legal status, being legally constituted and since then its struggle has been enduring and tireless.

We serve all people who are diagnosed with a blood disease, including all types of cancer, including Chronic Myeloid Leukemia. Every year we commemorate the World Day for the Fight against Chronic Myeloid Leukemia, with educational activities, health fairs, as well as the activities of the CML HORIZONS ADVOCACY.

Felice Bombaci

Gruppo AIL Pazienti LMC

Italy

How to contact me:

felice.bombaci@ailpazienti.it
+39 335 732 4754

MY STORY:

I was born in Messina (Italy) on 1958 and I live in Turin (Italy). My wife's name is Marisa and we have three children. My life with CML began in March 2000 after a normal blood tests. Through the Internet I knew a new drug STI571 (Imatinib). In 08/2000 I joined the IRIS clinical phase III trial at hospital "San Luigi" in Orbassano (Torino - Italy). I was randomized in Interferon + ARA C and took it until 12/2001 (terrible side effects).In 02/2002 I was switched on STI571. The disease has regressed: PCR negative since January 2003. In March 2014 I stopped treatment and I'm PCR negative - MR5.0

In October of 2009 with other patients I founded the "Gruppo AIL Pazienti LMC", the first Italian community of people with CML. I am the chair of this Group. Also actually I'm the Coordinator of AIL's Patients Groups for Hematological Malignacies

ABOUT MY ORGANISATION:

GAPLMC was established on 16 October 2009 in Rome. From the beginning it has been working to distribute information and raise awareness of CML to patients and caregivers and to promote and support research. The Group is entirely made of patients and families, and it hasn't got the aim to work instead of doctors, but to help patients to cope with the their illness, to share their experience with fellow sufferers. Since 2009 we have organized seven national patient information meetings with specialist speakers and several smaller local meetings to meet more informally. These meetings are extremely important occasions, as they provide an opportunity to meet up with the top experts and practitioners and to participate in an informal discussion regarding their quality life, new therapies, patient treatment options etc. We have also developed a website providing information on CML and a forum only opened to patients. Till now about 870 people have joined the forum, our "virtual square" where they freely contribute to the various discussions and communicate directly with other forum members. In addition, our group is involved in several international projects on quality of life, adherence to therapy.

Contact detail: Gruppo AIL Pazienti LMC Via Casilina, 5 00182 Roma (Italy) • infolmc@ailpazienti.it • http://www.lmconline.it

Gabriel Omar Tirelli Cartagena

ASUL

Uruguay

How to contact me:

rontirellig@hotmail.com
Facebook: Gabriel Tirelli

MY STORY:

My relationship to the association is through my wife, who had Chronic Myeloid Leukemia (CML).

Due to the situation we were going through, I became involved and decided to collaborate with whatever was within my power so that she, and all others with this disease could access all possible treatment opportunities in our country. This is how ASUL (Asociación Uruguaya de Leucemia y Afines) was born.

ABOUT MY ORGANISATION:

ASUL - Asociación Uruguaya de Leucemia y Afines

Created in 2006, achieved legal status in 2007.It is an association that defends the rights of patients. We all share the conviction that it is not easy to obtain timely access to treatments and information.

Our mission

- To aim to improve the quality of life of patients
- To provide emotional support to patients and their families.
- To provide information about the different treatment options.

Geir Knapstad

Blodkreft Foreningen

Norway

How to contact me:

geir.knapstad@gmail.com

MY STORY:

My story: I was diagnosed with CML in 2011 and quickly got in touch with Professor Bjørn Tore Gjertsen at the Research Department of Haukeland Hospital. He enrolled me in a study testing a new medicine, which was successful! I returned to my full-time position as a high school principal after 2 months until I retired in 2018. I have since used various versions of Gleevec and Dasatinib. I attempted to stop the medication twice, but without success. Now, I am using Imatinib 400 mg, which works perfectly. I live in the city of Florø with my wife Bjørg. She accompanies me to all consultations, conferences, and lectures related to the issue of blood cancer. My hobbies include hunting, fishing, and literature

ABOUT MY ORGANISATION:

My organization, the Association of Blood Cancer, has over 2400 members in Norway. Its main purpose is to contribute to a better life for its members, patients, and their families. Additionally, the association disseminates information about leukemia, especially regarding medical advancements and new treatment methods. The organization advocates for its members with politicians, authorities, and the healthcare system. Olav Ljøsne is the leader of the board.

Georges Sayde

CML Group Lebanon & Middle East.

Lebanon

How to contact me:

gfsayde@hotmail.com
Cmlgroup.me@gmail.com
www.cmlgroup-me.com
WhatsApp:009613805538

MY STORY:

I have been diagnosed with CML and put on Glivec in 2006. I started to search in the internet about my disorder and about Glivec. After communicating with other patients in Lebanon we have established this Organization .

I am in deep molecular respond since 2008 and still with Glivec last visit to my Doctor he advise to stop the treatment under his control.

ABOUT MY ORGANISATION:

CML Group Lebanon is a nonprofit association created in 2009 in Beirut, Lebanon. Our aim is to provide support, information and assistance to patient with Chronic Myeloid Leukemia (cml) and their families in Lebanon and Middle East. Our association is run by volunteers who vary from being CML patients themselves or relatives of CML patients . We encourage all other patients to join our organisation to assist in our goal. CML Group aims to gather funds to provide financial aid for CML patients. Organisation achievement:

Working closely with the Lebanese Ministry of Health to ensure the availability of the right Medication and to let the medication reachable to all Lebanese Patients. On the occasion of the world CML Awareness Day we announce our new transportation plan to help patient to have their PCR test every 6 month with round trip transportation from the Provinces to the City.

Gershon Tsegah

CMLAG

Ghana

How to contact me:

Kindly reach me via email:
fudeyltd@gmail.com
tel: +233 20 182 3211

MY STORY:

My journey began with the discovery of an abnormal surplus of white blood cells in my bloodstream, unearthed by a routine health check. After further testing and a Leukemia diagnosis in 2009, I went through a phase of denial and acceptance of an almost certain death for I knew, no amount of resources could cure cancer. Two years later, a serious bout of illness enrolled me into the MAX Access program (formerly GIPAP) at the Korle Bu Teaching Hospital. Now, I'm dedicated to CMLAG patients, ensuring access to treatment

ABOUT MY ORGANISATION:

Chronic Myeloid Leukemia Advocates of Ghana (CMLAG) is a non-profit association supporting patients with Chronic Myeloid Leukemia (CML) and their relatives, by sharing knowledge and best practices, running joint campaigns and educating advocates.

CMLAG provides a platform for patients, family, friends, researchers, physicians and donors, to come together to discuss clinical and non-clinical issues and treatment advances for patients with CML.

We provide; information on patient experiences, knowledge about combatting psychosocial issues, news on latest research and clinical trials and discussions on alternative treatment practices. Simply put; make people know more about CML.

Our mission; Informing the public on up-to-date CML treatment options; Creating awareness and prioritizing CML care in Ghana by collaborating with healthcare authorities; Building support groups at the local and national level and Working with groups of a similar orientation to share knowledge and advice. With approximately 200 members in our community, we continue to build a reputation as a trustworthy support group with our patients' best interests at heart.

Gissela Lizarme Ibañez

AGALEMO

Costa Rica

How to contact me:

Mail : gjlizarme@gmail.com
Phone : (506) 83438032
LinkedIn : Gissela Lizarme

Jacqueline Montúfar

The Max Foundation

Guatemala

How to contact me:

jacqueline.montufar@themaxfoundation.org
Tel.: +502 5949-5476

Jenneke Borst

Hematon - patient organization for people with blood cancer

Netherlands

How to contact me:

jenny.borst@hematon.nl
Phone: +31 (0)6 29443150

www.hematon.nl

MY STORY:

The fact of being a health professional does not make a difference with the other patients of CML. In February 2014, I had a medical check due fatigue, more than usual, and recurrent urinary trac infections. The diagnostic changed my professional life because I am expose to multiple infections processes that my immune system have to deal with. One month after using Gleevec, the spinal aplasia process started and three month later remission of the disease. As a doctor, insist on a healthy lifestyle that includes exercise and proper nutrition.

ABOUT MY ORGANISATION:

AGALEMO is a Costa Rican organization of patients diagnosed with chronic myeloid leukemia, multiple myeloma and other oncohematological diseases.

Its mission is to provide psychological, emotional and medical support to patients, family members, caregivers and people who are interested in blood diseases.

I have known AGALEMO for several years, especially the president Silvia Diaz who is also a CML patient.

MY STORY:

I work at The Max Foundation since 2019 as Local Program Coordinator for Central America & Caribbean; I am responsible for Mas Access Solutions (MAS) in these countries.

In this year, I have been in close contact with patients, caregivers and Physicians and MoH representatives.

I am based in Guatemala and have a Foreign Affair and Customs background.

ABOUT MY ORGANISATION:

The Max Foundation is a 25 year old US based non-profit organization established with the mission of accelerating health equity. Our focus is on supporting patients in low and middle income countries by decreasing health inequities.

Our flagship program is Max Access Solutions, an initiative that puts the patient at the center of the program and aims to provide access to any treatment the patient might need. Through a network of over 500 hematologists and oncologists, collaboration with 5 pharmaceutical companies who provide access to specific products; a partnership with an international distributor; and a robust program of wrap around support, today The Max Foundation has the largest NGO driven global access program for CML, providing access to TKIs to patients in 76 countries.

The organization is also active in access to treatment for GIST, Ph+ALL, CLL, Renal Cell Carcinoma, NSC lung cancer, and Breast Cancer.

MY STORY:

In 2016, I was diagnosed with CML. Since this diagnosis it was the 3rd time for me that I had a serious illness, I ended up on a merry-go-round, with the question: Why me again.

I could no longer carry out my work (Interim Management), and missed the work very much. I started working on volunteering at the Red Cross, refugee work and Hematon. The course of CML went well. In April 2020 I stopped taking the medication and it is still going well.

ABOUT MY ORGANISATION:

Hematon supports people with blood cancer or lymphoma, people (being) treated with a stem cell transplant, and their loved ones. Hematon offers reliable first-hand expertise and stands up for the patient's interests. We understand their questions and concerns.

Hematon promotes the interests of patients to the government, insurance companies, hospitals and scientific associations. We represent the patients perspective regarding to issues such as expensive medicines, cancer and work, scientific research and quality of care.

We provide easy ways to meet others with the disease, exchange experiences and learn from each other. Either online in our private Facebook groups, or at information and peer support group meetings near, attended by experts and fellow patients. They can talk directly and individually to someone with first-hand expertise.

Hematon shares information, to learn more about the diseases on hematon.nl with blogs, videos, and news about the latest medical developments. We also organize lectures via webinars by hematologists and other experts. Consult our coaches about cancer and work and let useful online tools help patients return to, or stay, at the workplace.

Members will receive the quarterly Hematon Magazine containing interviews, news and medical updates, as well as the digital Hematon newsletter.

The organization mainly consists of involved and (experiential) expert volunteers.

Ji Won Kim

KBDCA
(Korea Blood Disease & Cancer Association)

South Korea

How to contact me:

E- mail : kbca-give@daum.net
Phone : +82 10-9995-7328
Instagram User ID : kbdca

MY STORY:

I've been working at KBDCA for three years, and I'm helping patients with blood diseases and cancer. Before joining the company, my grandfather began to fight colon cancer, and I began to pay attention to the patients who were fighting the disease.Currently, I have been attracting sponsorship so that patients who are sick can receive various support. Also I am in charge of promoting KBDCA through the association's website and SNS.

ABOUT MY ORGANISATION:

KBDCA started in 1995 with the self-help group for patients with leukemia, which was established by three patients with leukemia to help patients with blood diseases fight and heal.After that, it was officially approved by the Ministry of Health and Welfare in 2002.KBDCA is helping people with blood diseases and cancer return to their daily lives and delivering hope for a cure through various programs such as refunding of drug costs and support treatment costs, online and offline medical education program with advisory medical staff, blood to help them fight the disease, and issuing a periodic publication "Hope" containing the latest medical information of advisory medical staff.

Joannie Clements

CML Buster Foundation
CML Buster Family Support Groups

USA

How to contact me:

Cell/WhatsApp +1 714-319-3193
Web: www.CMLBF.org
LkdIn: https://www.linkedin.com/company/CMLBF
JoanWClem@gmail.com or Joan.Clements@CMLBF.org
Facebook: /CMLBusters

MY STORY:

I am a 22+ year CML warrior, currently treating with the same TKI I started, and dealing with daily side effects. I continue to live my life and love being a wife, mother, grandmother, and great grandmother of a growing family.

I also continue to be a patient advocate and champion for CML patients who is dedicated to improving quality of survivorship for individuals affected by CML. After my diagnosis, I soon recognized the need for current verifiable CML information and the benefit of having access to others with the same diagnosis and similar journey. I especially learned of the importance of human connection being a valuable coping tool, and how the importance of communication between patient and physician can positively affect patient outcomes and QoL issues. Dealing with my own pesky side effects disrupting my daily routine for the past 22 years, I am lucky to have been on the same treatment for successful CML management which keeps "The Beast Snoring Not Roaring".

ABOUT MY ORGANISATION:

Since 2003, CML Buster's patient lead face-to-face family support group has continued to grow and meet in-person monthly. During Covid-19 in 2020, we converted to monthly Zoom meetings realizing the current isolation of that time and the need for more personal CML community outreach in the US. Today one (1) face-to-face support group and (three) 3 virtual support groups arranged by time zones, allow patients across the nation opportunities to chat with each other and share their CML journeys in the comfort of their homes, exchanging experiences monthly. CML patient participation continues to expand as this population continues to grow and live longer and thrive. As CML advocates, daily we help CML patients with challenges on how best to live well with CML by sharing personal experiences and acquired knowledge through life's journey.

CML Buster's warriors continue to rely upon support from each other and accurate up-to-date information drawn from many reputable US and international sources, like CML Advocates Network, iCMLf, Leukemia & Lymphoma Society, and NCCN, as we address issues unique and present in the US. This amazing group of warriors go to battle against CML daily, continuing to guide each other toward the best possible CML outcomes and QOL. We are a family fighting in full force for a fulfilled life and aim to be positive examples of living successfully with CML.

In 2019, I cofounded CML Buster Foundation (CMBF) which has provided the finance and structure to support and expand our US CML outreach. CMLBF continues the mission of empowering patients, educating, advocating, comforting, offering an understanding heart, and giving inspiration and HOPE during their lifelong blood cancer journey.

I serve as CEO and VP of Mission at CMLBF. I am proud to serve on many advisory boards, committees and panels in the US as a CML "Patient Expert".

Joseph Henry Enorense Edosomwan

MaxCare Nigeria

Nigeria

How to contact me:

maryjoe872002@yahoo.com

MY STORY:

I was diagnosed with CML in 2016, after fighting an ulcer for a hole year. It was not easy with doctors uncertainty. But with the help of the President of Max care Nigeria, friends and family we have gotten here today. I pray for a better understanding of CML and a cure to come. Its is a journey of uncertainty but a thanks to Max Care.

ABOUT MY ORGANISATION:

MaxCare Nigeria is a CML support and advocacy group formed by patients who have CML and GIST in Nigeria. As a group, we strive to provide support (emotional and health-advice) to patients living with CML, equip them with knowledge about the disease and advocate for improved access to treatment; while also drawing stakeholders attention to the challenges accessing proper treatment in Nigeria.

Jung Sook Park

KBDCA
(Korea Blood Disease & Cancer Association)

South Korea

How to contact me:

E- mail : kbca-1@daum.net
Phone : +82 10-3204-8689
Instagram User ID : kbdca

Kairi Jets

Estonian Leukaemia and Lymphoma Patients' Society

Estonia

How to contact me:

info@leukeemia.ee

Lisa McNeil

Chronic Myeloid Leukaemia

Australia

How to contact me:

lisajmcneil@hotmail.com
+61 414 679 558

MY STORY:

I am a social worker with 22 years of experience.I joined KBDCA in 2002. I was in charge of educational programs, newsletters, and planning drug cost support programs. Also I have conducted drug compliance education and campaigns such as Gleevec and Tasigna.

In 2015, I left the KBDCA for a while and worked for a Autism Society of Korea for about four years as a General Manager, conducting policy proposals and awareness improvement campaigns for people with Autism, and returned to the KBDCA in 2022.

Currently, I am in charge of the entire business as a working-level manager of KBDCA, focusing on pharmaceutical company cooperation projects, activities to urge insurance benefits for new non benefit drugs, also advocacy activities to listen to and convey patients' opinions.

ABOUT MY ORGANISATION:

KBDCA began in 1995 as a self-help group formed by three leukemia patients who agreed to improve the "poor fighting environment." At that time, leukemia was recognized as a disease for children and there was a lack of support system to help adult cancer patients, so they gathered together to build a support system with the intention of helping each other, and the need for organized activities was raised. It was launched as a non-profit public interest corporation approved by the Ministry of Health and Welfare in January 2003.

KBDCA invites prominent domestic noted doctor to provide correct disease-fighting information through more than 100 disease classes per year, and helps 50,000 cancer patients annually through a drug cost refund program. Activities urging the introduction of new drugs, insurance benefits and campaigns to improve awareness are being conducted to help patients recover quickly and return to their daily lives.

MY STORY:

I first encountered the topic of CML after joining Estonian Leukaemia and Lymphoma Patients' Society as first a volunteer, and 6 months later as a Board Member. My reason for joining the organization was an AML diagnosis, an acute blood cancer where the problematic blood cells are the same type as with CML.

ABOUT MY ORGANISATION:

Estonian Leukaemia and Lymphoma Patients' Society (Eesti Leukeemia- ja Lümfoomihaigete Liit, or ELLL for short) stands for the rights of all blood cancer patients in Estonia and provides information about those haematological diseases to patients, their loved ones and the wider public.

The society was established in October 2005 and one of its first aims was to add Glivec (active substance imatinib) to the list of medicinal products reimbursed by Estonian Health Insurance Fund. Within the framework of the campaign 'For life', support signatures were collected in shopping centres and during sporting events and sister organisations from other European countries sent letters of support. In June 2006, the Glivec aim was achieved, and a year later the society began to represent lymphoma patients as well.

In addition to leukaemia, and lymphoma, the society now also represents people with myeloma and myeloproliferative disorders.

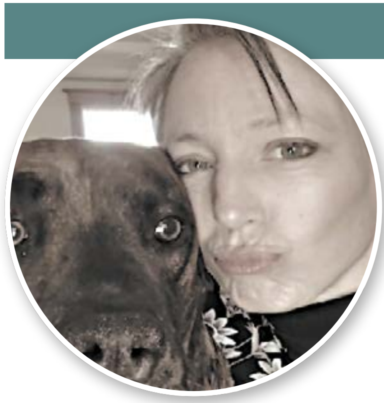
MY STORY:

I am a long term CML patient, diagnosed in 2001. My first treatment was Interferon then a number of TKI's to being one of the early participants in the Phase 1 clinical trial of Ascinimib. My husband and I have two beautiful children all of whom have been by my side for this long journey.

ABOUT MY ORGANISATION:

We are a new organization and the first CML specific organization in Australia. Myself along with Dr Ilaria Pagani a CML researcher have co-founded Chronic Myeloid Leukaemia Australia. With my experiences as a long term patient and Dr Pagani's passion and drive for providing a better outcome for patients with CML has seen us become good friends over a number of years when I was first introduced to her as a CML patient consumer. We will be providing education resources, advocacy and support and awareness of CML to patients, family members, carers and the general public. We are excited to begin our journey and promote awareness of CML in our community and the ongoing need for research and fundraising. We look forward to learning more from the experiences of other CML organizations and reporting on our achievements.

Lisa Machado



Canadian CML Network

Canada

How to contact me:

isa.machado@outlook.com
Websites: cmlnetwork.ca
Iamlisamachado.com
Insta: @iamlisamachado

Lise-lott Eriksson

Bloodcancer in focus

Sweden

How to contact me:

Phone: +46 707 764443
E-mail: lise-lott@lmerikssonbygg.se

Livingston Simiyu

Henzo Kenya

Kenya.

How to contact me:

Email: stonielivi21@gmail.com
Email: secretary@henzokenya.or.ke
Cell: +254724587326
LinkedIn: Livingston Simiyu

MY STORY:

I was a financial writer when I was diagnosed with CML in 2008. Those early days were so difficult. I wasn't feeling well and I was so scared that I would die and leave my kids without a mom. Fast-forward 16 years, and I feel so grateful to have seen my kids grow up, and for all the great people I have met in the CML community. I now write about healthcare advocacy for a national newspaper in Canada and regularly speak at conferences about patient engagement, drug access and health policy.

ABOUT MY ORGANISATION:

The Canadian CML Network is a national organization in Canada that supports people living with chronic myeloid leukemia. Our biggest event happens once a year, the "Living Well with CML" conference, and brings together people with CML, their families as well as healthcare experts from across the country.

MY STORY:

Chairman of Swedish Blood Cancer Association for 8 years, president of MPE, Myeloma Patient Europe since 2022, board member of the Cancer Research KI in Stockholm at the Karolinska Institute in Sweden. Started my patient engagement as a patient advocate after being diagnosed with essential thrombocythemia in 2011. Also used to be a caregiver to my father with myeloma.

Trained and started my working career as a physiotherapist. Then continued to a higher degree in health science and business administration management. Has worked with management in private healthcare and also as CEO and co-owner of a family company in the building construction business.

ABOUT MY ORGANISATION:

Newly started platform in Sweden in November 2023 reaching out to all affected by bloodcancer, cancer and other blood disorders in Sweden. A non-profit patient organization mainly focusing on health care policies affecting research and science, drug development, patient access to clinical trials, innovative cancer treatments and patient involvement in HTA.

MY STORY:

I am a Chronic Myeloid Leukemia survivor and have been on treatment for just over 10 years. I am passionate about Cancer Advocacy and Awareness among young adults and especially medicine justice. I am a Lawyer by profession and currently interested in pursuing Law and cancer Policy both Locally and or Internationally.

For the past six years I have been on the Board of Henzo Kenya as Secretary to the Board. I am also the seating Chairperson of Henzo Youth whose focus is Emotional and Economic Support to young adults on CML treatment.

ABOUT MY ORGANISATION:

HENZO KENYA, is a Non-Profit, Community Based Organization Registered in Kenya. It was originally a support group for Chronic Myeloid Leukemia (CML) and Gastro-intestinal stromal tumors (GIST) patients, but has since expanded its mandate to accommodate patients and caregivers of Acute Myeloid Leukemia (AML) and Acute Lymphocytic Leukemia (ALL) who are drawn from all over the country. Currently, we have about 2,000 members from across Kenya, about 1,200 of them being CML patients.

Our Mission is: To create awareness about Leukemia and GIST, provide emotional and social support to members and to advocate for mainstreaming of issues related to the diseases that affect patients and general public. Our Vision is to be the hub of information, psycho social and emotional support for Leukemia and GIST patients and a key advocate for the same. The goals and objectives of Henzo are to reduce Leukemia and GIST mortality and morbidity rate in Kenya. To achieve the above goals, Henzo Kenya holds Support meetings regularly and occasionally holds education Days where the patients and their caregivers, get time to interact with Healthcare professionals to learn more about the disease, how to optimize treatment, nutritional priorities in the course of treatment and other important information. Henzo Kenya, through support from friends and partners has held these support and educational activities consistently over the last 15 years.

Liviu Ciprian Salceanu

CML RO

Romania

How to contact me:

Ciprian.salceanu@gmail.com
+40732010010

Loretta Williams

CML Zimbabwe Trust

Zimbabwe

How to contact me:

arthurherronzw@gmail.com
Tele; +263 772144766

María Valdebenito

Corporación Maxi-Vida

Chile

How to contact me:

maria.valdebenito.olave@gmail.com
+56 9 8642 4070
Facebook: Corporación Maxi-Vida Chile
www.maxivida.cl

MY STORY:

Diagnosed in 2016 I started my journey as a patient and wanted to learn a lot about my condition and help others navigate this condition with the best tools and info.

ABOUT MY ORGANISATION:

The Romanian Association of Rare Cancers - ARCrare was founded in June 2011 from the desire to represent people affected by rare cancers in Romania, their families and specialists involved in their diagnosis and treatment.

CMLRO is the future association dedicated to CML patients. By founding it we want to reach, first of all, all CML patients in Romania. To integrate them in support groups, to teach them how to live with a rare disease, to know what rights they have, and to be always informed about the disease they have.

MY STORY:

I was diagnosed with CML in 2004, and told I could live for 3 to 5 years depending on how well (Hydrea) would work. Not accepting 3years and I prayed so hard for 5 years as my youngest son was only 15 so I wanted to leave a young man not a boy.

Now 20yrs later, I was blessed to meet 8 of my 10 grandchildren and to be a meaning full part of their lives, while still here to give hope to many newly diagnosed CML Patients.

ABOUT MY ORGANISATION:

CML Zimbabwe trust was established in 2016 as a non profit organization. The goal of CML Zimbabwe trust is to reduce the leukemia &GIST mortality rate in Zimbabwe through its four main objectives:

1.Support : To establish support systems such as counselling and support groups for leukemia & GIST patients, survivors and families .

2. Information; To establish a coalition to mobilize resources for Leukemia & GIST and advocating for health concerns to be mainstreamed in relevant government and non governmental agencies.

3 .Research :To research the availability of resources for people diagnosed with Leukemia & GIST and identify existing information gaps and needs

4 ..Awareness :To design and implement awareness and training workshop and seminars based on information derived from the research.

MY STORY:

I started working at Maxi-Vida because I wanted to help as many patients as I could. About 22 years ago, I was diagnosed with CML and I realized there wasn't much information, and even less was shared with us. That was the moment I started working intensively towards improving access to treatments, providing information and mainly emotional support to everyone who needs it. Having CML and being a patient's advocate has changed my life, that's why I want to change others' lives in the same way.

ABOUT MY ORGANISATION:

We are a Chilean Patients' Organization, founded legally in 2008. Our organization is focused on providing information, counseling, and emotional support for patients with CML and other types of leukemia. Our mission is to improve our patients' quality of life and reintegrate them back into their regular activities as actively as possible. We also contribute with scientific data, given by renowned physicians, about the condition and all the treatments currently available. We also organize regular meetings and group activities so all members from our organization can meet, share life experiences and give support to each other.

Maria Esther Palma

Luz de Esperanza

Perú

How to contact me:

Esther_palma35@hotmail.com

Mariam Izoria

The Max Foundation

Georgia

How to contact me:

mariam.izoria@themaxfoundation.org

Mehriban Baghirova

Charter of "Fighting Leukemia" Public Union

Azerbaijan

How to contact me:

mehriban63@mail.ru
+994556773258

MY STORY:

Mi nombre: María Esther Palma Sebastián. Presidenta Ejecutiva de la asociación LUZ DE ESPERANZA PERÚ, soy Licenciada en educación y sobreviviente de LMC. Desde hacen 18 años, Soy casada y tengo dos hijas DAMARY Y NICOLE, las cuales ya son mayor de edad y profesionales.

I was diagnosed with CML 16 years ago. That moment was very difficult for me, but with time I understood that it was God's purpose that I would help many patients with this pathology, because I had the experience of having my medicine stolen from me, together with other 3 patients. At that moment, I began fighting for the rights of CML patients. Sadly, the other 3 patients passed away because they did not have medicine, but I was able to help other patients access theirs.

ABOUT MY ORGANISATION:

Luz de esperanza es una asociación civil sin fines de lucro creada para apoyar a las personas con cáncer a la sangre, enfermedades de alto costo y familiares que no están organizadas.

Luz de Esperanza is a non-governmental organization, created by CML patients. Luz de Esperanza stands up for the rights of patients with hemato-oncological diseases, who need treatments with high-cost drugs. Our work is focused on advocacy, educational talks for patients and caregivers, psychological support, meetings with decision-making authorities like congressmen, ministers and the National Health Superintendence (SUSALUD). We help patients access the different hospitals in Peru, for their care and treatment.

MY STORY:

Educational background: MD, MPH, PhD in Public Health and Epidemiology.

Professional milestone: Years of experience working in the National Center for Disease Control and Public Health in Georgia, Chief epidemiologist based in the CDC country office in Georgia.

My journey in The Max Foundation: Since the 2018 year I have had the privilege of leading programs as a Program Officer in the Asia Pacific, Eastern Europe, and Central Asia region.

ABOUT MY ORGANISATION:

The Max Foundation is a 501 c 3 non-governmental organization, that was established to honor the memory of Max Rivarola who passed away from chronic myeloid leukemia in 1991 at the age of 17.

Our mission is accelerating health equity, we do this by delivering medication, technology, and services to patients facing cancer and other critical illnesses, focusing our energy on those no one else is helping!

Our vision is a WORLD where all people can access high-impact medicines, where geography is not destiny and, where everyone can strive for health with dignity and hope! We believe all human life has equal value, we believe achieving health equity requires a holistic approach, we believe progress requires dedication beyond the ordinary. We believe we must develop innovative solutions!

MY STORY:

I was born in Baku, Azerbaijan, on January 11, 1963. After the death of my only brother, I decided that I would help other children who are ill. Since 1999, I am a volunteer at the Hemophilia Association. When I was offered to help children with leukemia in 2006, to be honest, I was scared, because I saw in the hemophilia association what difficulties they faced. I thought I didn't have the strength to do this job. But when I was diagnosed with CML, I realized that this was my mission. Since then, I have been the director of our organization. It is the duty of every person to do best and help people who need us. After all, Only Together We are Powerful!!!

ABOUT MY ORGANISATION:

Our organization helps patients with leukemia. We buy medicines, food and provide legal support.

In order to provide support to patients, we hold sales exhibitions, fairs and blood donation events.

Our organization began its activities in 2006. Over the years, we have helped more than 1000 children and more than 300 people with CML recover. Meetings are held with patients, their problems are listened to, and patient schools are held.

Milena Remic

Slovenian Lymphoma and Leukemia Patients Association, L&L

Slovenia

How to contact me:

E-mail: milena.remic@gmail.com
FB: Milena Remic

Milica Kuzmanoska

HEMA-Association for support of patients and caregivers of Hematology diseases

Macedonia

How to contact me:

milica@hema.org.mk
+38970349550

Mohammed Jaafar

Leukemia Patient Care Association

Iraq

How to contact me:

E-mail: cmliraq@yahoo.com
Phone: 00964 7702610111

MY STORY:

Co–founder and vice president of Patient Association, L&L. Diagnosed CML 2005 in accelerated phase, 2006 stem cell transplantation from unrelated donor, since 2008 on imatinib which keeps my disease under control. Active in Patient Association L&L: coordinating and working on projects for patients and for rising awareness; working with patients&families, support groups.

M.Sc.in informatics by profession, live with my family near capital city Ljubljana in Slovenia.

ABOUT MY ORGANISATION:

Slovenian Lymphoma and Leukemia Patients Association, L&L, is a non-profit organisation that connects patients with lymphoma, leukemia, multiple myeloma, MDS, and other blood diseases. It was formed in 2007, by 5 co-founders – patients

Key objectives of L&L: timely detection of disease, holistic treatement & care, quality life with the illness & after it. Helping patients and relatives, promotion of health and healthy lifestyle.

Key projects/activites of L&L: publishing&distributing info materials for patients; individual and group meetings with patients and medical specialists; patient days and events, workshops, roundtables, national awareness campaigns; influencing positively the Slovene health policies.

Membership in umbrella organisations: Myeloma Patient Europe, Lymphoma Coalition, CML Advocates Network, The MDS Alliance, Slovenian Philanthropy

Contact: www.limfom-levkemija.org,
e-mail: limfom.levkemija@gmail.com

MY STORY:

I am a singer-songwriter of Macedonian Folk music for almost 25 years and during my work, I have had the opportunity to meet different type of people from all around the world during my travels. Through a chance meeting with Lidija Pecova, we developed a close friendship and I shared with her my desire to be able to give back to the community and after careful consideration doing some research and realized that there is an unmet need for patients and caregivers together with 3 more of our colleagues we took on the challenge and we formed HEMA. Patient advocacy gives me an opportunity to use my voice to give back to my community who still continue to support me through my music

ABOUT MY ORGANISATION:

Association HEMA Skopje is a voluntary, non-profit, non-governmental, non-partisan organization. HEMA is dedicated to changing outcomes of patients with hematology diseases and support caregivers by strengthening patient advocacy in this area. Our goal is to deliver tailored support to patients and caregivers on a national level while joining forces with institutions (Government and non-governmental), Physicians and other organizations to review and assist with the reform on healthcare policies and research across the country in order to provide patients with current therapies and a better quality of life. The health system has always been a challenge in Eastern Europe but in Macedonia even more so. The hugest problem in our region is access to modern therapy, especially for hematological malignancies. HEMA is actively working on strengthening patient knowledge about their disease, treatment options, how treatment and care should be provided and their rights as patients. This will be my first patient conference and as we have a number of MPN patients I am actively working with currently this will help me to learn more about MPN's see how other organisations work and share experiences so that I can bring this knowledge back to my own country.

MY STORY:

I'm Mohammed Jaafar, I am CML patient from 2007 and I'm taking Tasigna 200 mg. Founder and president of the Leukemia Patient Car Association in Iraq from 2011 which have 2,250 patients. Founder and president of the CML Arab Network. Participated in many global, Arabian and Iraqi CML conferences such as CML Horizons 2014 in Serbia, 2015 in Barcelona, 2017 in Frankfurt and many conferences in Dubai, Beirut and Baghdad.

ABOUT MY ORGANISATION:

The Leukemia Patient Care Association in Iraq working on provide the medical treatment to the Iraqi CML patients in cooperation with the Iraqi ministry of health and working on the patients education about CML.

And we organizing awareness and educational conferences and workshops about the disease for CML patients.

Muhammad Raftaz

Kiran

Pakistan

How to contact me:

ayani4u@gmail.com

MY STORY:

I am Muhammad Raftaz Kayani (Associate Professor of Physics serving in Islamabad Model College For Boys H-9 Islamabad). I have joined this organization ten years ago when one of my cousins became the patient of CML. I have been introduced to this organization by Mr. Ashar and Salim Mirza who were actively working with the Max Foundation. By the cooperation of Max Foundation I became able to provide all the required medicines to that patient almost for three years. The miseries of the patient had been reduced sufficiently but finally she died. I was much impressed by the cooperation tendered by this organization. I decided to work with this organization to help the deserving CML patients and I am glad to say that I have contributed a lot to this cause.

ABOUT MY ORGANISATION:

Name: KIRAN; When established: 2009

Your reach: Number of members: 06; Average age: 40-50; Male/female breakdown: 04/02; Numbers of people your organisation supports:900

Aims: To mitigate the miseries of the humanity specially in the field of health.

Main projects:

- Provided emotional and motivational support to 900 CML patients.
- Provided shelter to the patients during their visits to hospitals and labs.
- Provided limited financial support to deserving patients.

Nabil Belhassen

CML TUNISIA

Tunisa

How to contact me:

Mail: maitrebelhassen@gmail.com
Cell: +216 98 442 153
Messenger: facebook.com/nabil.belhassen3

MY STORY:

I was diagnosed with CML in August 2009. I died and then I lived again

Because i discovered that life with cml is full of challenge and happiness this disease help me better understand the meaning of life

ABOUT MY ORGANISATION:

CML Tunisia is the first and only specialized association of CML patients,

Its objectives are to help patients, advise them, guide them, elevate their morale and encourage them in life to achieve happiness,.

Theassociation has carried out several activities, including defending patients rights to receive quality treatment , it also participated in the reform of the health system at the level of Tunisian government,

Despite the difficulties encountered by the association on several levels, its members continue to fight to always remain at the service of CML patients

Because human life is precious to us, we exist & we co-exist.

Finally we hope peace, health and courage to all cml patients

Nádia Marques

APCL

Portugal

How to contact me:

nadiamarques@apcl.pt

MY STORY:

Portuguese Association against Leukemia (APCL) was founded in January 2002 by a group of patients who have survived hemato-oncological pathologies (leukemias and lymphomas) doctors from the Portuguese Institute of Francisco Gentil (IPOFG) of Lisbon who treated them. The APCL's founders' main motivation was raising awareness and mobilizing civil society to support all those who fight daily against the devastating disease of leukemia. The mission of the APCL is to contribute, at the national level, the efficiency of the treatment of leukemias and other associated hematological neoplasms.The main objectives to which APCL sets itself are:

– Developing and Maintaining the Register of voluntary bone marrow donors in Portugal

– Promote the advancement of scientific knowledge on the nature, evolution, prevention and treatment of these diseases, support scientific research with a scholarship program and invest in advanced training for health professionals;

– Providing financial and psychological support, as well as other means to improve the quality of life for hematologic oncology patients and their families.

- Managing a accommodation house (CASA PORTO SEGURO) in Lisbon for patients and their families/caregivers who are required to leave their home areas to access more specific treatments or a bone marrow transplant.

ABOUT MY ORGANISATION:

My name is Nádia Marques. I was born in Luanda, Angola, and I came to Portugal after the independence war. I am 44 years old and hold a degree in Social Work. I have worked with various populations, including at-risk children and youth, individuals with profound disabilities, and the elderly. Currently, I serve as the Director of Casa Porto Seguro.

Throughout my professional life, the dimension of health and patient empowerment has been a mission for me. More recently, I find myself experiencing the challenges faced by a close family member who has leukemia and their struggle to overcome the obstacles inherent in the recovery process

Nataliia Lopina

CFP «DROP OF BLOOD»

Ukraine

How to contact me:

nataliia.lopina@gmail.com
+3809699658227
linkedin.com/in/lopina-nataliia-1bab99160/
facebook.com/profile.php?id=100006231796903

MY STORY:

I am a cardiologist and cardio-oncologist. My aunt developed acute imatinib liver toxicity in 2016. Since 2017, I have been actively involved in assisting other patients in overcoming various types of toxicity associated with CML treatment. I provide lectures and consultations for CML patients with the support of CFP "DROP OF BLOOD" and Professor Iryna Dyagil. Additionally, I have contributed to a research group focused on developing new clinical algorithms for managing TKI hepatotoxicity, cardiotoxicity, and cardiovascular risk prevention in CML patients.

ABOUT MY ORGANISATION:

BFR "BLOOD DROP" is an organization registered in Ukraine in 2015. Our organization includes both patients and their relatives. About 3,000 people in total.

The main goal of our organization is to explain to patients with CML that life does not end after diagnosis.

CML diagnosis is not a death sentence!

Our goal is to achieve 100% provision of CML patients with all available treatment methods!

Our achievements over the past year, despite the great war in Ukraine, are as follows:

- all patients are provided with imatinib, nilotinib, bosutinib, dasatinib.
- patients from the zone of active hostilities have moved to European countries or the western regions of Ukraine and are receiving the necessary treatment.
- 3 state clinics in Ukraine already perform TCM from non-family donors.

Nick Duncan

CML UK – Facebook Group

United Kingdom

How to contact me:

Nick.Duncan@uhb.nhs.uk

MY STORY:

I am a consultant haematology pharmacist and member of CML UK – Facebook. I work at the Queen Elizabeth Hospital in Birmingham and have been looking after patients with CML since 2016. I co-created the recently launched MyCML app with fellow pharmacist Andrea Preston. We have been working closely with Nigel Deekes from CML UK and David Fitzgerald from CML Support in promoting the app to CML patients as well as undertaking patient-focused research projects.

ABOUT MY ORGANISATION:

Founded CML UK, a Facebook group, back in 2012, we now have 4500 members in the UK and worldwide. Additionally I am also a moderator on CML worldwide, where we have approximately 6000 members.

Our Facebook group is a closed group so only members are able to see and respond to comments. This is something that was wanted as feeds were going out to members own personal pages and so being seen by anyone, some patients do not of course, wish their family or friends to know of their illness. Within a closed group, members can be frank amongst fellow CMLer's.

CML UK was set up to enable patients and carers to come together and share experiences, advice and knowledge. These two groups are very helpful, particularly to those that have been recently diagnosed.

I firmly believe we all have to work together to give all avenues of help to patients and so thank other groups and members here for

Nirmesh Prakash

Friends of Max

India

How to contact me:

Linkedin:
www.linkedin.com/in/nirmeshprakash-gr owthadvisor
Email:
nirmesh.prakash@gmail.com

MY STORY:

As a Trustee & the Secretary of FOM, I have the honour and the responsibilities to work towards helping thousands of CML/GIST patients live their lives to their fullest.

As a part of the FOM Managing Committee, I contribute by bringing structure, processes & ideas to help FOM best utilise the available resources.

I was diagnosed as a CML patient in 2004

ABOUT MY ORGANISATION:

Friends of Max (FOM) is The World's largest CML & GIST. Patients Support group, based in India. The recognized Support Group Arm of The Max Foundation in India spread across the country with 40+ City Chapters.

FOM's core activities include: Organising regular face-to-face meetings for patients with treating physicians aiding & facilitating access to monitoring diagnostic tests for financially challenged patients. Organising events to spread cancer awareness & the importance of compliance, training volunteers to help patients live a positive & productive life and representing the interests of the patients in domestic & global forums.

Ozgun Tansoker

Dance with Cancer

Turkiye

How to contact me:

ozgunt3@yahoo.com
info@kanserledans.org

Parvana Panahova

Charter Of "Fighting Leukemia" Public Union

Azerbaijan

How to contact me:

parvanapanahova@gmail.com
+994515376843

Pasusant Wattanaboonya

Thai CML Patient Group

Thailand

How to contact me:

Email: pasusant63@gmail.com
Mobile: 66-89-178-6867

MY STORY:

I was diagnosed cml in May 2008. I started to use Gleevec on June 19, 2008. I was in remission for 7 years with Gleevec until 11 June, 2015. Now, I am Free Remission and still undetectable since 11 June 2015. I would like to thank 'CMLAdvocates' for giving me the courage with precious speakers, information about cml, and the chance to know other patients from all around the world. God bless all of us :)

ABOUT MY ORGANISATION:

I have been working as a volunteer for 15 years.

Our aim is to support patient and their relatives.

Me as a CML patient and a patient advocate, I established,

http://www.kmlturkiye.com

This web side is still the only and interactive web side about cml. I am supporting cml patients and their family and redirect to the right information.

MY STORY:

In 2014, I was admitted to the Physics Faculty at Baku State University. My involvement with organizations began precisely during my undergraduate studies. In 2017, coincidentally, my encounter with a child suffering from leukemia increased my interest and dedication to this field. While volunteering as a teacher for them, I realized that there was much for me to learn from them. The resilience of these young warriors has always amazed me. Since then, whether as a regular volunteer or as a lead coordinator, I have taken many steps, and will continue to take them, to ensure a more comfortable treatment period for leukemia patients. Currently, I am a member of the board of directors at the Leukemia Fight Public Association."

ABOUT MY ORGANISATION:

Our organization specializes in providing assistance to leukemia patients. We procure medicines, food, and offer legal aid to those in need. To further support patients, we organize sales exhibitions, fairs, and blood donation drives. Established in 2006, our organization has been dedicated to aiding leukemia patients. Throughout the years, we have aided over 1000 children and more than 300 individuals with Chronic Myeloid Leukemia (CML) in their recovery journey. We regularly engage with patients, attentively listen to their concerns, and conduct patient schools to provide education and support.

MY STORY:

DonI have been living with CML for 25 years with 5 years on TFR now. I am currently working as a volunteer for 2 patient advocacy groups i.e. a committee of Thai CML Patient Group and Founder of MPN Patient Advocacy Group Thailand.

ABOUT MY ORGANISATION:

Thai CML Patient Advocacy Group has been established in 2010 with approx. 600 patients under the consultancy of the Thai CML Working Group chaired by Professor Saengsuree Jootar, Faculty of Medicine Ramathibodi Hospital.

Our key objectives are to provide the most updated CML information to patients, care-givers and also to carry out activities for the benefit of our members and public.

Patricio Fabián Vaca Castro

Bekämpa CML Foundation

Ecuador

How to contact me:

fundacionfublec@yahoo.com
pbacaco07@hotmail.com

MY STORY:

I was diagnosed with CML in November 2008, I had an initial treatment of three years of chemotherapy, I managed to access the first tyrosine kinase inhibitor (imatinib) in 2011, and I developed resistance to it after three years, so I had to advance to second-line treatment (Nilotinib).

Finally, I intend to empower patients in Human Rights so that they can demand dignified and humane treatment.

ABOUT MY ORGANISATION:

The Bekämpa Foundation arises from the need for patients to organize themselves, in order to access the public health system and demand adequate health care, permanent delivery of medicine through legal actions.

We have understood that Human Rights protect us to demand the right to life, access to adequate medical and pharmacological treatment.

Pepo Levi

CML Macedonia

Macedonia

How to contact me:

pepolevi@yahoo.com
+ 389 70 268423

MY STORY:

Having been diagnosed with CML in 2006, I started on Hydroxyurea and Interferon, and I was in a lot of pain. There was a moment when I thought the world was ending. Within a few months, I was enrolled in a Novartis clinical trial, and I received Glivec from Novartis. Following that, I resumed my normal routine with Glivec and my pain subsided. Thus, I decided that CML Macedonia would continue to fight for modern medicines and appropriate treatment for every patient with CML in Macedonia. Additionally, I have just been appointed President of the Association of Jewish Communities, where we intend to work hard.

ABOUT MY ORGANISATION:

I founded the Association for the Help of Patients with CML in the Republic of Macedonia in 2007. Our association aims to care for patients with CML, as well as to put Glivec on the reimbursement list of drugs covered by the Macedonian Health Insurance Fund. As a result of many press conferences, public appearances and TV debates, we were able to win this battle. A decision was announced by the Steering Committee of HIF in Macedonia on 27th of April 2011 to reimburse and make Glivec available for Macedonian CML patients. Our team also managed to provide Nilotinib to approximately 20 patients in 2018. Additionally, Dasatinib and Ponatinib were donated to one patient by the Hematology Clinic. But our activities do not stop here. We will continue to care for CML sufferers and request that all TKI's be placed on the reimbursement list. We will also continue to advocate that each patient is provided with regular BCR-ABL monitoring. We believe that regular BCR-ABLE checkups will allow a certain number of patients to eventually transition to TFR, where they can lead their lives normally and without medication.

Reynaldo Esquivel Núñez

Asociación Mexicana de Leucemia Gist

Mexico

How to contact me:

reynaldo.esquivel@ameleg.org.mx

MY STORY:

En el año 2010 por invitación me incorporo a formar parte dela mesa directiva y soy nombrado como secretario y apoderado legal, mis funciones son principalmente la organización de conferencias con especialistas en salud así como en solicitar medicamentos en donativos o al menor costo posible para

pacientes que no tienen seguridad social y de escasos recursos, también en apoyarlos y capacitarlos para exigir sus derechos ante las autoridades en salud.

ABOUT MY ORGANISATION:

Una de las principales acciones es la capacitación y empoderamiento de los pacientes y familiares para exigir a las autoridades del sistema de salud laa tención y dotación de medicamentos, así como a las personas de escasos recursos sin seguridad social, el que tengan medicamentos donados o a un costo que esté a su alcance pagarlos, por medio de conferencias el que aprendan de su enfermedad los síntomas y tratamientos adecuados al igualque los efectos secundarios que pueda ocasionarles.

Samineni Sudha

The Max Foundation

India

How to contact me:

Email address
sudha.samineni@themaxfoundation.org

Šarūnas Narbutas

POLA (Lithuanian
Cancer Patient Coalition)

Lithuania

How to contact me:

sarunas.narbutas@pola.lt
+370 652 22852
@lietuvai

Shiao Ning Tarynn Oei

Hematon

Netherlands

How to contact me:

Email: tarynn.oei@hematon.nl
Facebook: Tarynn Oei
0031-640466910

MY STORY:

Patient Advocate and Programme Officer.

I work closely with Patient Support Groups in South Asia Region and manage Max Access Solution programs in India and Nepal.

ABOUT MY ORGANISATION:

The Max Foundation is a nonprofit global health organization that provides cancer patients in low- and middle-income countries with access to lifesaving treatment and care.

Today, we provide services to over 30,000 patients in more than 70 countries, including access to over 10 million daily doses of medicine yearly.

Our patient services include efforts to expand access to molecular diagnostics, educational workshops, and one-on-one care. The Max Foundation supports physicians in diagnosing and monitoring patients in areas where patients have no access or cannot afford diagnostic testing.

MY STORY:

Diagnosed with CML in 2006.

- Still on imatinib 600 mg, stable PCR of 0,002%
- Did campaign for access to imatinib in 2007, collected 180 000 signatures in Lithuania (6% of all population), which eventually led to 100% reimbursement of all lines of targetted therapies to all CML patients in Lithuania
- Have been involved in international patient advocacy for 12 years
- Attended 12 CML Horizon conferences

ABOUT MY ORGANISATION:

- POLA is an umbrella organisation for all cancer patients (including CML) in Lithuania, currently uniting 27 organisations that represent over 100 000 cancer patients in Lithuania
- POLA has 120 people, who are engaged in projects on a weekly basis
- We provide social, legal, psychological, nutritional support for cancer patients and their carers
- We represent patients (and their carers') interests at all levels of decision-making processes, from high-level meetings, to working groups and governmental committees
- We are being interiewed by media over 100 times per year
- POLA representatives deliver over 70 presentations at various policy events per year
- We are partnering with more than 180 commercial organisations in Lithuania
- We have an updated database of 11000 active cancer patients who are using POLA services
- Every assistance we provide to cancer patients and their carers is completely free

MY STORY:

CML has been diagnosed since March 2018. I previously worked as a general practitioner in a health center in Amsterdam for 20 years. Treated with Nilotinib, Dasatinib, Bosutinib and Ponatinib. Ultimately good response with Asciminib.

ABOUT MY ORGANISATION:

Hematon is the dutch patient organization for people with blood or lymphatic cancer and for people who have undergone a stem cell transplant. Hematon stands for more healing and a better quality of life. We believe it is important that patients can participate in society again. We also draw attention to prevention and palliative care.

The HOVON contact group consists of advocates who participate on behalf of Hematon in one of the HOVON working groups. The HOVON working group consists of hematologists who shape the guidelines for the treatment of CML in the Netherlands. Hematon comments from a patient perspective on study proposals, guidelines and other initiatives of that working group.

Shova Karki

Blood Cancer Society NEPAL

Nepal

How to contact me:

So_waah@hotmail.com
977 9841902447
Face book: so_waah
Instagram: sowaah

MY STORY:

I am Shova Karki, from Nepal. By profession I am a travel agent and working as a corporate coordinator at Gorkha Travels Pvt. Ltd.I was diagnosed with CML in year 2001 where I underwent treatment with HYDROXY UREA and INTERFERON for almost 2yrs . On 2003 I was enrolled under GIPAP program and started GLIVEC since then . From past 4yrs (from 2015) I haven't taken any medicine but getting a complete MMR which indeed is a very good result .

ABOUT MY ORGANISATION:

- Blood Cancer Society Nepal was established on 21st Dec 2007 with 7 members working till now as a core members .
- We primarily focus on care of patients and make them avail with the treatment.
- Raise awareness about CML and GIST
- Addressing the problem help to find the solution
- Besides above we provide social,psycological , legal support to cancer patients and their care taker
- 3-4 activities are performed yearly where cancer patients and care taker meet. These activities has facilitate a communication platform for them where they can cope up with the problem they are with and share the fact they are living with ..

Silvia Castillo de Armas

ASOPALEU

Guatemala, C.A.

How to contact me:

asopaleulmc@gmail.com
sirecaa@gmail.com
Phone: (502) 5201 4130
Facebook: @Asopaleu
Twitter: @asopaleu
Linkedin:Silvia Castillo de Armas
Instagram: castillodearmas

MY STORY:

21 years of living full with a diagnosis that has had great advances in its treatment, providing health, hope and good living conditions to the vast majority of patients, living with CML around the world. Adequate adherence and monitoring have given me the opportunity to continue with my life and enjoy the triumphs in life of each of my children, family and friends. I enjoy every moment, because that is life. I dedicate my time to supporting, helping and guiding patients and families who have touched by cancer, transmitting gratitude, hope and updated information to learn to navigate our health systems.

Grateful to God and the people who opened my mind, from whom I have learned and continue to learn every day.

Thank you, to those who have been part of this change in my last 21 years of life.

ABOUT MY ORGANISATION:

20 years serving as a bridge of support and providing hope to patients with leukemia, GIST and referral for patients diagnosed with different types of cancer, who are referred to where appropriate for their treatment and medical care. We are part of: Alianza Latina, CML AN, Aliaza GIST, ALAN, LLC AN, UICC (Global Newtork Member), GEPAC Latam, Guatemala AL Network, beneficiary medicine´s donation program in Order of Malta Guatemala. Main pillars: Education, information, emotional and social support, professional support with Psycho Oncologist and Psychiatrist. Strategic alliances with other private non-profit entities for care, treatment and palliative care for low-income patients and those undergoing treatment in private entities. We work completely ad honorem and we have the recognition and support of doctors who are members of the Guatemala Hemato Oncology Association.

ASOPALEU - "United for life and hope"

Sirirat Saeyang

Max Smile Support Group

Thailand

How to contact me:

Mail : keekeeyyy@gmail.com
Phone : +66 8313990
Line : keesirirat
FB : SinYee Bkk
Twitter : @_KeeYang_
IG : KeeYang

MY STORY:

I was diagnosed as CML which changed my life forever. By surprise CML didn't change my life to bad way but to the better. I quit my job, begin new life. I begin to travel which is always what I want to do. Turns myself in to Tour Guide. Enjoy everyday life

Today,I am healthier, stronger and happier. Own a Travel Agent company. Happy everyday.

In the other way round I feel grateful having CML. Otherwise I will never be what I am today.

ABOUT MY ORGANISATION:

Max Smile Support Group

Groupobjectives: To meet between patients with leukemia - CML and other rare cancers to support each other. Also sharing of advice, experience and self-care. Especially for those new patients who have just been diagnosed with cancer. They will need support both heart and mind.

Tatiana Aguila

Hope and Life

Ecuador

How to contact me:

tati_ag24@hotmail.com

Facebook: Asociación Ecuatoriana de Ayuda a Pacientes con Cáncer "Esperanza y Vida".

MY STORY:

I am Tatiana Aguila Vera and I come from Ecuador. Since 2011, I am part of the Ecuadorian Association Assistance for the Cancer Patient "Hope and Life", in which I am currently the head of the Marketing and Institutional Relations.

I started working with the Association after my mother was diagnosed with Chronic Myelogenous Leukemia (CML), thankfully she has been resilience and as a family we have overcome through that difficult situation. For this reason, I consider it's important to participate in this event because I can get updates and information, that I can share with the Ecuadorian patients and to the ones that are part of the Association.

ABOUT MY ORGANISATION:

La Asociación Ecuatoriana de Ayuda a Pacientes con Cáncer "Esperanza y Vida", is a non-governmental public service organization that provides education, prevention and advocacy for patients with oncological and hematological problems in the community, support in psico social and affective approach in order to educate and motivate patients and families on their health and rights in comprehensive care to improve the quality of life of patients to integrate their work and social activities.

Teresita E Dumagay, MD

The Max Foundation

Philippines

How to contact me:

tesdumagaymd@gmail.com

MY STORY:

I started working with patients with CML and the Max Foundation during my training in Hematology in the Philippine General Hospital. While there are still challenges in the management of CML in the Philippines, the Max Foundation has helped bridge some areas and has improved the quality of life of patients with CML. It has been my privilege to continue working with them through out the years.

ABOUT MY ORGANISATION:

The Max Foundation helps Filipino patients access medications, tests and services that are unavailable in the Philippines.

Toni Montserrat

Pacientes LMC

Spain

How to contact me:

tmontserrat@gmail.com
+34.669.004.790
facebook.com/toni.montserrat
twitter.com/terratremol66

MY STORY:

Diagnosed in September 2015, aged 48. After trying to continue working normally, I had to accept that I could not do it. The main reason was that I lacked strength, I woke up (and I wake up ...) tired, with bone pains, joints, anxiety, stress, fog brain ... My hematologist did not recognize the side effects as such.

Looking for quality information on the web, I discovered that in other countries the culture of patients was very different, than in Spain, and with a few "bad blood brothers" created this group, to try to act as real advocates.

I do not have much "productive time", but with a computer and some hours a day, I want to learn and share. I am a proud EUPATI fellow.

ABOUT MY ORGANISATION:

We are a group of patients, created in mid-2016 and officially registered in January 2017. Our main objectives are:

- Participate in initiatives of public recognition of the needs of CML patients.
- Defend the rights of patients (due to side effects of the disease itself or the medication in front of the Medical Courts, or by an adequate pharmaceutical prescription and not conditioned by economic issues).
- Participate in the definition of the Quality of Life policies of chronic patients (mainly Cancer)
- To collaborate with the Health Administrations in the elaboration of policies of social and medical support.

We have already developed an international survey of patients to patients: Https://goo.gl/O78gg6 (also available in English: https://goo.gl/YuFYVi) and we want to continue collaborating and learning. And with a very clear code of conduct:

- Always be guided by ethics and objective criteria marked by CML patients and never by industry or other people's estates.

To seek positive and useful results for the CML patient community, without seeking profit in any case.https://www.facebook.com/groups/LMCEShttps://twitter.com/LMC_PACIENTESpacienteslmc@gmail.com

Uyvichheka Chhim

Max Miracle

Cambodia

How to contact me:

Tel: +85599444312
Facebook: Uyvichheka Chhim
Email: uyvichheka.chhim@yahoo.com

Yair Bar-David

Israeli CML Patients Organisation

Israel

How to contact me:

yair.bardavid1948@gmail.com
Mobile phone- +972-50-8803332

Yamina Daban

LMC France

France

How to contact me:

mdlmcfrance@gmail.com

MY STORY:

My name is Uyvichheka Chhim. I am 35 years old. I was diagnosis with CML since 2015. I have been with CML for 20 years. Currently, I am taking Aciminib 400ml a day and getting my treatment with Dr. Chuah Charles at Singapore General Hospital in Singapore.

ABOUT MY ORGANISATION:

Max Miracle is CML support group that was founded in August 2012.

The purpose of forming up the group to support CML patients through their hardness and sharing experience by providing CML awareness.

We have about 80 members now and we just got new team members,. We planned to do the fundraising to support CML patients for thier traveling to pick up the medicine at the hospital.

We are planning to have our patient support group meeting back this year as we have not been so active because of covid 19

MY STORY:

I am a Paediatrician working in Soroka Medical Center , Beer-Sheva, Israel . My wife, Hannah, was diagnosed with CML 15 Years ago. .After short time with Interferon she started Gleevec 400 mg a day and is doing very well. From the beginning I became involved in the activities of the Israeli CML support group and consult members of our group in regard to medical problems, (related and not related to CML),

how to read and analize laboratory results, interaction of Gleevec with other medicines and so on. For the last 4 years I am the chairman of the comitee of the Israeli CML group.

ABOUT MY ORGANISATION:

I decided to use my experience to help other CML patients and founded the Israeli CML Patient's Organisation in April 2001 with 7 local patients at a small hospital in the city of Netanya, Israel. It has since grown to support more than 230 patients from around the country.

The organisation conducts monthly meetings with presentations on various CML-related topics and organises CML awareness social activities. Most of the CML experts in Israel have appeared at the organisation's events in addition to experts like Dr Talpaz from the USA and dr Philipp Le Coutre from Germany.

We have launched in 2006 a web site, www.cml.org.il, the first one to address this disease in Hebrew.

We are also involved in other activities like getting needed drugs approved for patients, lobbying at the parliament, field tours of labs and more. The highlight of our activities is an annual CML Awareness weekend, which we have been organizing the last 6 years, at different hotels around Israel, with more than 200 patients and caregivers.

MY STORY:

Mina DABAN is the President and founder of the association « LMC France » (Leucémie Myéloïde Chronique France).

Mina DABAN is also a member of the "European CML Advocacy" and of the "CML Advocates Network" as well as an elected member of its international steering committee. Mina was personally diagnosed with CML in 2003. With her first treatment, she experienced very severe side effects causing her to be bedridden for 6 years. However, thanks to the progress in medicine, with her present treatment, she is now once again trying to live an active life by dedicating her time to informing and improving the quality of life for others who share her situation which has given her the determination to create and carry on with LMC France. She stopped TKI since 2013. She originally studied law at the University of Marseille, and consequently was in charge of the regional organization in the professional training sector for adults. Under this heading, she developed training projects in coordination with different ministers. In 2014 she obtained a university degree "therapeutic education" at the medicine University of Marseille (France). In 2016, she obtained a university degree " Engineering of e learning" at the University of Rouen (France).

In 2018, she created an online training the «e-university LMC France»

ABOUT MY ORGANISATION:

Established in February 2010, LMC France is the first association of CML patients in France, today counting over 2 500 members. LMC France provides information, resources and support to CML patients and their families. LMC France aims to develop through all means any actions related to chronic myeloid leukemia (CML). The association also brings together patients and families to assist them in their fight against the disease through research, information and support events. LMC France is the organizer of various innovative events as well as the creator of the "WORLDWIDE CML DAY». The first event was held, symbolically, on September 22 2011, and was followed all over the world. With these fundraising events the proceeds are handed over to groups to advance research in the field. Since 2010, LMC France is a referenced website with information approved by the renowned members of the scientific committee. There is also support for patients and their families with use of social networking and shared spaces, meetings, psychological support, creation of patient tools (eg: LMCoach, the 1st ever e-health continuous coaching service for patients suffering from CML), e learning training: e-university LMC France. As well as achievements that give hope such as: songs, CDs, photo contests, photo exhibitions, videos and newsletters.

Yervand Hakobyan

CML-Armenia

Armenia

How to contact me:

+37477450683
yero75@yahoo.com

MY STORY:

Since 2014 we started our work for CML patients. Me, my colleagues and CML patients founded "CML-Armenia" patients' group. The main purpose of our organization is to help patients with CML to have the best diagnostics and treatment. We are organizing educational meetings, translating educational books and materials. Also we are doing activities to raise awareness about CML

ABOUT MY ORGANISATION:

"CML-Armenia" patients' group

has been founded in 2014 by professionals and young patients to spread necessary information about disease and treatment among patients with CML disorders in Armenia. The aim of our organization is creation of well-informed CML patients' community.

Yolima Méndez

Colombian Leukemia and Lymphoma Foundation

Colombia

How to contact me:

presidencia@funleucemialinfoma.org
www.funleucemialinfoma.org
Facebook: Funcolombiana De Leucemia Linfoma
Instagram: funcolombiana

MY STORY:

I´m wife and mother of 3 beautiful children: Santiago, Tomás and Mariana. I´m psychologist Master in Epidemiology and Health Public.

In 1998 my grandmother was diagnosed with CML, she died a year later. In 2007 I founded the Colombian Leukemia and Lymphoma Foundation. Since that year I work in our mission and to achieve our vision, as responsible for networking, fundraising and advocacy.

ABOUT MY ORGANISATION:

We are a none profit organization founded in 2007 that offers emotional and social support, information and advice to children with cancer and their parents, and to adult patients with hemato-oncological diseases. We educate the patient in their diagnosis, treatment, self-care and health system.

To achieve our aims we carry out awareness campaigns, congresses, educational days, support groups, research studies and advocacy. We work in collaboration with several health care centers in the cities of Bogotá and other cities in the country. Each year we impact the lives of nearly 200 children with cancer and their families, as well as 1,500 adults with leukemia, lymphoma or myeloma.

Funcolombiana promotes a philosophy of love for life and re significance of the cancer experience. We are Life Inspirers.

Yujin Hong

Zero Club

Republic of Korea

How to contact me:

cafe.daum.net/cmlzero
82+10.3050.8210
rebornedj.2014@daum.net
instagram: @dreamingj.writer
www.canfcoop.com

MY STORY:

I am cancer-survivor who suffered from CML blast-crisis in 2013 and had a bone marrow transplant in 2014. As a writer, I published 3 books. My second book is the "Welcome to Anti-cancer World" which is a true story about overcoming my disease. Third book is "Life is beautiful" which is published by cancer survivors and their families. In 2023 as a president, i'm working on Canfcoop for the psychological and economic recovery of cancer patients and their families. Also I am taking care of straycats.

ABOUT MY ORGANISATION:

Zero Club is an online community centered on patients and their families.

We launched an online community in 2006. Our board of directors consists of a total of 8 members, including the chairman. Currently, the total number of members registered in the online community is almost 2,800 people.It is operated for the purpose of exchanging hope, courage, our stories with each other and helping patients and their families for a better life.

Zero Club shares disease-fighting stories, encouraging and supporting activities for CML patient & their families, care giver, etc. We also invite doctors to mentor patients with other organizations and hold talk concerts to communicate with CML patient & their families, care giver, etc. Of course, we attend every CML Horizon to learn new global CML patient care, share them with Korean CML patients and glow together..

Yuliia Skliarova

CFP «DROP OF BLOOD»

Ukraine

How to contact me:

sklyarovayulechka2@gmail.com
+380958130397

MY STORY:

Hello, I'm Yulia, I'm 34 years old. I learned about my CML diagnosis on March 9, 2022, a few days after Russia's aggression against our country and the start of a full-scale war. I lived in Donbas, but because of these events I was forced to leave my native home. From that moment I faced two wars, for my life and for my country. Imatinib therapy, unfortunately, did not give results. I am currently on Nilotinib (Tasigna) - 800 mg per day. I love life, family, dog and active lifestyle... .

ABOUT MY ORGANISATION:

CFP "DROP OF BLOOD" is an organization registered in Ukraine in 2015. Our organization includes both patients and their close relatives.We unite about 3,000 patients in Ukraine.The main goal of our organization is to explain to patients with CML that life does not end after diagnosis.CML diagnosis is not a death sentence!Our second goal is to provide medicine and diagnostics to CML patients during the war in Ukraine.Our goal is to complete two important tasks!

CML
HORIZONS
HYBRID MEETING 2024

For full Who is Who profiles visit link:
https://cmlhz.cme-congresses.com/
(Door “Who is Who)

or scan the code:

WHO IS HERE

From our sponsors

Alexander Schulte

Novartis Pharma AG
Medical Director,
International Medical Affairs

NOVARTIS

Switzerland

How to contact me:

+49 151 34158903
alexander.schulte@novartis.com

MY WORK SUPPORTING PATIENTS

I am a medical affairs specialist working in hematology supporting the improvement of patient relevant inputs & outputs in clinical trials and the education of patients to make patients understand their disease better and to be as informed as possible when discussing with their caretakers.

Alexey Salamakha

Director,
Patient Engagement

NOVARTIS

Novartis

Switzerland

How to contact me:

C +1 862 210 0869
Email alexey.salamakha@novartis.com

MY WORK SUPPORTING PATIENTS

I drive end-to-end integrated patient engagement and patient advocacy activities in close collaboration with Global Development, Medical Affairs, Corporate Affairs, and Commercial functions at Novartis.

My goal is to cultivate mutually beneficial working relationships with advocacy groups worldwide and to help serve the needs of patients.

I joined Novartis in 2012 after 5 years with Global Healthy Living Foundation, a non-profit organization supporting people with rare and chronic conditions.

Beatrice Baudino

Novartis
International AG

NOVARTIS

Switzerland

How to contact me:

beatrice.baudino@novartis.com

MY WORK SUPPORTING PATIENTS

As Head Ethics, Risk and Compliance for Patient Engagement at Novartis, I provide strategic direction and operational guidance across ethics, risk and compliance matters for Patient Engagement. This enables Novartis associates to engage in partnership and co-creation with the patient community and adhere to laws and regulations, as well as professional standards and accepted business practices.

Deimantė Stankevičienė

SIA Novartis
Baltics Medical
Engagement Partner,

Lithuania

How to contact me:

+370 606 78185
deimante.stankeviciene@novartis.com

Elzbieta Zawislak

Head of Public Affairs
Incyte Corporation

Switzerland

How to contact me:

ezawislak@incyte.com
Phone: +41 21 581 52 00
Mobile: +41 795 85 43 16

Katharina Ambühl

Patient Advocacy &
Hematology
Novartis

Switzerland

How to contact me:

katharina.ambuehl@novartis.com
+41 79 570 25 73

MY WORK SUPPORTING PATIENTS

I am working closely with different patients advocacy groups in Lithuania to better understand their needs and provide solutions which could improve their lifes.

MY WORK SUPPORTING PATIENTS

A strong believer in patient empowerment, I head the Public Affairs team at Incyte, Region Europe, focusing on advocacy, education, and strategic partnerships. I am committed to ensuring that patient needs are at the center of decision making for the leaders at Incyte. I believe that by bridging the sensitive divide between a company and key external stakeholders, like Patient Organisations, we can champion advances in health policy, fostering a healthcare ecosystem with equitable access to services and treatments, improved health literacy, increased patient involvement in medical research and adequate patient representation in policy-making processes.

It was through work with the CML patient organisation in Poland nearly 20 years ago that I first learned about the challenges patients face and the role of the supporting and vocal patient community. I then had a great pleasure of contributing to the CML Advocates Network projects that shaped my understanding of the transformative power of patient voice: the adherence survey and the first draft of the “patient-friendly” ELN guidelines.

MY WORK SUPPORTING PATIENTS

I am the CML Patient Advocacy Lead. In this role, I define Novartis’ patient advocacy priorities in CML and oversee advocacy group collaborations that educate and activate patients to seek optimal care, break down barriers to patient access, and bring patient insights into the company.

I am an economist by training and have more than 30 years business experience in various areas including marketing, strategy, communications and physical and mental wellbeing. In my free time I do a lot of charity work supporting children and young adults living with a disability.

Kenneth Wong

Sr. Clinical
Trial Manager

Terns Pharmaceuticals

USA

How to contact me:

Phone: +1 650-684-0436
Email: kwong@ternspharma.com
Study Email: CARDINAL@ternspharma.com
LinkedIn: www.linkedin.com/in/kennethwong2215

MY WORK SUPPORTING PATIENTS

Hello CML Advocates! I help manage the CARDINAL (TERN701-1012) Phase1 Dose Escalation & Expansion study in chronic phase CML patients. My goal is to bring novel therapies to patients in need through safe, efficient, and effective clinical trials. I oversee study site selection, startup, enrollment, and on-study management in the EU, USA, South Korea, and Australia. I am proud to be able to deliver patients more treatment options to improve outcomes and change lives!

Lucy Setian

Director Patient
Experience Strategy &
Solutions, Hematology

Novartis

Switzerland

How to contact me:

https://www.linkedin.com/in/lucysetian/

MY WORK SUPPORTING PATIENTS

Lucy leads the design of the international patient experience strategy, solutions and services for the hematology portfolio of Novartis. Prior to her role, she was leading the HealthTech strategy of the Novartis Foundation with focus on catalyzing innovative public-private partnerships and technology innovation models to support underserved and under resourced populations. Lucy is a technologist and a business executive with 16 years of experience in digitalization, marketing and business innovation strategy across life sciences, global health, public sector, FMCG, mobility, media, sustainable development.

Philibert Goulet

Regional Compliance
Officer

Incyte Corporation

Switzerland

How to contact me:

Pgoulet@incyte.com
+41 79 507 91 26

MY WORK SUPPORTING PATIENTS

Being Compliance Officer, I ensure that all our interactions with Patients and Patients Advocacy Groups (PAG), as a Pharmaceutical Company, are handled ethically and in compliance with applicable laws and codes.

We want to respect the independence of PAGs, ensure our interactions have a clear purpose and are transparent, and always maintain the highest level of integrity.

I am proud that Incyte sponsors CML Horizons, making such critical event possible!

Fun fact: in a previous role, I have been a founding member of a EUPATI country National Platform!

Sophie Goessens

Bristol Myers Squibb
Associate Director,
Congress Excellence

Switzerland

How to contact me:

Sophie.Goessens@bms.com

MY WORK SUPPORTING PATIENTS

Currently spending 6 months in the Hematology Patient Advocacy team to learn and gain insight knowledge.

As part of my mission, I am working on the specific topic of "what does health equity and unmet needs" mean for the many Patient advocacy groups around the world.

Swapna Shenvi

Sr. Director,
Medical Affairs
Terns Pharmaceuticals

USA

How to contact me:

Phone: +1 650 683 6860
sshenvi@ternspharma.com
www.ternspharma.com/

MY WORK SUPPORTING PATIENTS

Terns is committed to improving the lives of those with CML. This starts by bringing the patient voice into every aspect of our work. We want to learn by listening, to gain an unbiased understanding of the patient experience, and experience how the patient voice can enrich and inspire the work that we do every day.

Patti Jewell

Senior Director, Global
Policy and Public Affairs
Pfizer Inc

United States

How to contact me:

+! 646-402-4829
Patti.Jewell@Pfizer.com
www.Pfizer.com

MY WORK SUPPORTING PATIENTS

Pfizer is in relentless pursuit of breakthroughs that change patients' lives. We innovate every day to make the world a healthier place. It was Charles Pfizer's vision at the beginning and it holds true today. My work focuses on supporting public policy change to improve access to the cancer medicines patients need to live better and longer lives. I'm passionate about working with advocacy organizations, as well as other external and internal stakeholders to advance access to care.

Expression of Gratitude to Our Sponsors

We express our sincere appreciation to the sponsors below for their unwavering commitment to providing essential educational funding.

Without their generous support, this conference would not have been achievable.

Initiating sponsor:

NOVARTIS

Sponsors:

Pfizer

Incyte | SOLVE ON.

Bristol Myers Squibb

TERNS
PHARMACEUTICALS

Takeda | ONCOLOGY

LEUKEMIA & LYMPHOMA SOCIETY®
fighting blood cancers

Go Vilnius