

# WHO IS WHO



**LEARN, SHARE, GROW**  
Mini Virtual Conference

# MANAGEMENT TEAM



## Natasa Hace

MPN Advocates Network  
Belgium / Slovenia

### *How to contact me:*

hace@mpn-advocates.net  
info@mpn-advocates.net



### **MY STORY:**

I am Slovenian, currently living in Belgium, with background in EU health policy and cancer advocacy. I campaigned for cancer patients' rights and for putting cancer back high on the EU policy agenda at a EU-level cancer patient group, European Parliament and as a part of Slovenian EU Presidency which focused on improving cancer policy in the EU.

I live just outside Brussels with my Franco-British husband and my three children.

I am delighted to have joined MPN Advocates Network to be able to continue with my dedication to support people living with cancer.

### **ABOUT MY ORGANISATION:**

MPN Advocates Network was founded by representatives from several MPN patient support groups as a way of creating and maintaining collaboration between these organisations and providing a platform for joint activity.

**The objective of the organisation is to enhance MPN patient care by collaboratively:**

- Acting as an international collective representative of MPN patient groups, interacting with healthcare funding, treatment approval, and treatment research organisations
- Sharing best practice of support and advocacy activities between all patient groups
- Sharing available information on all current treatments, technologies and research results
- Encouraging cooperation between advocates, researchers, clinicians, and health care organizations
- MPN Advocates Network operates purely for the benefit of MPN patients and acts independently of any other organisation or company.

<https://www.mpn-advocates.net/>

# WHO IS WHO PROFILES



## Amy Lane, MBA, MSW

The Leukemia and Lymphoma Society  
United States



### *How to contact me:*

[Amy.lane@lls.org](mailto:Amy.lane@lls.org)

1-914-821-8303 (Direct Line)

1-800-955-4572 (Information Resource Center)

### **MY STORY:**

I am an Information Specialist at The Leukemia and Lymphoma Society. We speak one-on-one with patients, caregivers, and others to assist them through cancer treatment, financial and social challenges,

and give accurate, up-to-date disease, treatment and support information. Our team is comprised of master's level oncology social workers, nurses and health educators.

### **ABOUT MY ORGANISATION:**

The mission of The Leukemia & Lymphoma Society (LLS) is: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS exists to find cures and ensure access to treatments for blood cancer patients. We are the voice for all blood cancer patients and we work to ensure access to treatments for all blood cancer patients.



## **Dr. Angela Fleischman**

**University of California**  
**United States**

*How to contact me:*  
[agf@hs.uci.edu](mailto:agf@hs.uci.edu)

### **ABOUT MY WORK TO SUPPORT PATIENTS:**

Dr. Angela Fleischman is a physician-scientist investigating hematologic malignancies. She integrates her research with the clinical care of patients with these diseases.

Fleischman's longstanding interest in blood cell development began during her PhD graduate studies at Stanford. After completing her MD and PhD at Stanford, in 2005 she moved to Oregon Health & Science University (OHSU) for her internal medicine residency and medical oncology fellowship.

She joined the University of California, Irvine in July 2013 to develop her independent laboratory group focusing on the pathogenesis of myeloproliferative neoplasm (MPN). Her laboratory focuses on the role of inflammation in MPN. Her overarching research goal is to identify what drives disease initiation in MPN and to ultimately translate her scientific discoveries into therapeutic benefit for MPN patients.

## Ann Brazeau, CEO

MPN Advocacy & Education International  
United States

### How to contact me:

[abraiseau@mpnadvocacy.com](mailto:abraiseau@mpnadvocacy.com)  
1.517.899.6889



### MY STORY:

Ann Brazeau, CEO, has been working in the MPN community since 2005. Ann spent eight years at the MPN Research Foundation and launched MPN Advocacy & Education International in 2013.

Ann has been unwavering in her efforts to ensure all patients receive quality care and have access to current treatments. Ann's work in education, outreach and advocacy began early in her career, including the creation of screening programs for breast cancer and prostate cancer patients who were uninsured or under-insured. Those programs exist today. Ann also created a work/life program for women living in poverty to prepare them for the workplace, and offered counsel and direction to resources for quality health care.

### ABOUT MY ORGANISATION:

MPN Advocacy & Education International provides educational programs, materials, and resources for patients, caregivers, physicians and entire healthcare teams to improve their understanding of three myeloproliferative diseases, polycythemia vera, myelofibrosis and essential thrombocythemia. We are dedicated to making a difference in the lives of those affected by MPNs and strive to grow awareness and advocate on behalf of the entire MPN community. Host up to six educational programs per year. Dr. Ruben Mesa, the Mayo Clinic, is our scientific advisor and frequent speaker.

### ADVOCACY INITIATIVES

#### Vietnam Veterans with MPNs

Advocating on behalf of Vietnam veterans and others who believe their MPN was related to frequent exposure to Agent Orange/Dioxin

#### Women & MPNs

Host an annual educational program in the US focused on the challenges women face with MPNs

#### Pediatric MPN

Partnered with an MPN pediatric specialist and have begun outreach efforts to parents. Will host the first Pediatric MPN educational program in 2017

#### Health Literacy

Establishing a health literacy program



## Annemiek Eppingbroek

MPN Stichting  
The Netherlands

*How to contact me:*

[Annemiek@mpn-stichting.nl](mailto:Annemiek@mpn-stichting.nl)  
+31631079065

### MY STORY:

Till October 2016 I really had no idea what a MPN was. Because of hair loss my GP tested my blood. My blood counts were sky high, and one week later I was diagnosed with PV, Jak 2. My treatment so far was: Ascal and phlebotomy. Because of increased blood levels I started with Pegasys this month. I graduated as a psychologist and I worked as a manager in a health care organization. Because of my PV I had to quit with that. Since the end of 2018 I am a board member of the 'MPN Stichting'. My dream: That there will be a cure for MPN. And until that time: That people with MPN get the best possible treatment.

### ABOUT MY ORGANISATION:

The 'MPN Stichting' (Dutch MPN foundation) is an organization that provides its members with information about MPN, medication, treatment options, etc.

The 'MPN Stichting' promotes and creates opportunities for contact with fellow patients in various ways. By telephone, by internet forum, by its own magazine Pur Sang and by an annual meeting for all members. There is also a private Facebook group.

The 'MPN Stichting' is in contact with medical specialists, pharmaceutical companies, other patient-organizations and is supported by a medical advisory board of MPN specialists.

Last year we wrote a new brochure for our patients, with a lot of information about ET, PV and MF and how MPN can affect people in daily life.

The 'MPN Stichting' was founded in 2003. It is a voluntary organization that receives subsidy from the Dutch government. There are more than 1200 members.

## Armin Dadgar

MPN-Netzwerk eV  
Germany

### *How to contact me:*

a.dadgar@mpn-netzwerk.de  
+49 179 5294579



### **MY STORY:**

My father died in 2006 on a stem cell disease (amyloidosis) so I was a bit worried when I received my PV diagnosis in 2008 (after 9 years search for the origin of elevated blood values)

As I am still quite healthy only receiving ASS and phlebotomy watch and wait was more watch and worry. I then joined the mpn-network and their information helped me a lot. I am active in the forum and try to support the other patients especially newly diagnosed as good as possible.

Also active as mpn patient deputy in the G-BA for the assessment of additional benefits of medicine.

### **ABOUT MY ORGANISATION:**

Self help group for patients and family members of patients with mpn

About 1000 Members

Mostly active in Germany, Switzerland and Austria

Main support by an online forum and also regional meetings

Collaboration with doctors and researchers from the german mpn study group (gsg-mpn)

Organization of yearly meetings with expert presentations (currently online only)



## Bahija Gouimi

AMAL Association  
Morocco

*How to contact me:*

[bahijagouimi@gmail.com](mailto:bahijagouimi@gmail.com)  
[amaleucemie@gmail.com](mailto:amaleucemie@gmail.com)

### MY STORY:

I am a CML patient since 2002. At that time, my drug wasn't available in Morocco, so I had to travel and bring it from Spain every month for three years.

When I was diagnosed with CML, I was pregnant and my suffering was double, I was terrified of this new word "CML" and of losing my Baby. I am still hearing this doctor telling me that I had only 3 or 4 years to live.

When my hematologist said that I had a good prognostic since I succeeded to have the treatment, she gave me HOPE and I decided to create a CML Patient Group in Morocco in order to support other patients.

Today, CML is just a disease and I celebrate life each Day.

### ABOUT MY ORGANISATION:

AMAL means HOPE in Arabic:

AMAL is The first CML patient group in Morocco and north Africa to support patients with leukemia and similar diseases.

AMAL was founded in April, 16th, 2011, in Marrakech by 30 patients and parents. Now we are more than 500 members.

Our objectives:

- Providing support to patients and families
- Improving access to proper treatment and correct monitoring to all patients
- Raising awareness and fighting cancer stigma
- Educating patients and parents (producing educational materials, videos, organizing patient meetings, storytelling sessions ...)
- Advocating to improve policies and decisions in favor of cancer patients
- Improving the quality of life of patients and their families
- Sensitising public authorities and the civil society to material and moral constraints of CML patients
- Encouraging voluntary work as well as donation values to help patients in need
- Building a **PATIENT HOME** to patients and parents who live far from hospital
- Collaborating with physicians and medical authorities in order to improve communication and care conditions in Morocco.

**AMAL , which means HOPE in Arabic language**

## Brina Žagar

Slovenian Lymphoma and Leukemia  
Patient Association, L&L  
Slovenia

*How to contact me:*

[brina.zagar@gmail.com](mailto:brina.zagar@gmail.com)  
+386 40 524 366



### MY STORY:

I was diagnosed with non-Hodgkin lymphoma in 2006 and was successfully treated with chemotherapy and radiation.

In 2014 I started to work in Slovenian Lymphoma and Leukemia Patient Association, L&L, first as a student. Now I am employed in the organisation as a project manager and I am very grateful for this opportunity.

### ABOUT MY ORGANISATION:

Slovenian Lymphoma and Leukemia Patient Association, L&L, is a non-profit organization that unites patients with lymphoma, leukemia, multiple myeloma, myeloproliferative neoplasm, myelodysplastic syndrome and other forms of blood diseases together with their caregivers, friends and health professionals. The L&L Association strives for the timely detection of disease, holistic treatment and care of the patients, for better quality of life with the illness and after treatment, and helps patients' caregivers.

The L&L Association publishes and distributes informative brochures about diseases and treatment. We organize individual and group meetings, lectures, workshops and roundtables. One of the most important programmes is comprehensive rehabilitation for patients with blood cancers, which is supported by Ministry of Health. Each year we organize a national awareness campaign.

We work in collaboration with oncologists from the Institute of Oncology Ljubljana, hematologists from Slovenian hospitals and with numerous health professionals.



## **Cheryl Petruk**

**Canadian MPN Research Foundation**  
**Canada**

*How to contact me:*  
[cmpnrf@gmail.com](mailto:cmpnrf@gmail.com)  
780 940 6569

### **MY STORY:**

My husband had an MPN Blood Cancer. In 1992 he was diagnosed with ET, in 2010 it transformed to MF.

In 2018, he lost his battle with MF.

It has become my passion to serve the MPN community to the best of my abilities to help in providing better education, better resources, and more and better treatment options for patients.

I also believe that we need to assist the families as well, with support in living with an mpn blood cancer.

### **ABOUT MY ORGANISATION:**

The Canadian MPN Research Foundation has been established to fund and stimulate research and research projects for MPN Blood Cancers in Canada.

The CMPNRF will work closely with all stakeholders to achieve its mission, vision values and goals.

The CMPNRF was established in 2018 and its board of directors have passionate and close ties to the MPN Blood Cancer.

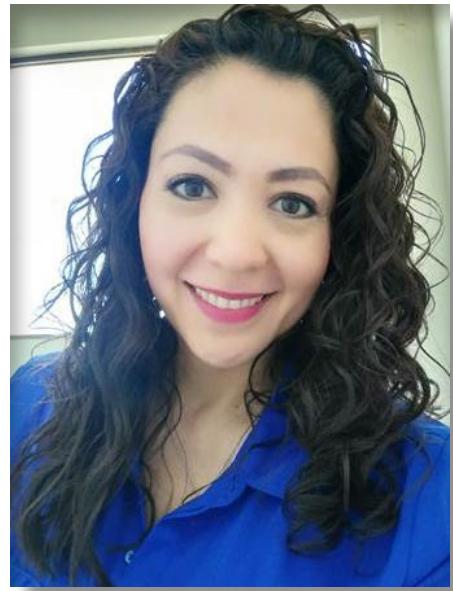
The CMPNRF will work closely with the Canadian MPN Network, Patient education group to ensure that all patients have the most up to date education, resources and information about MPN Blood Cancers in Canada and from around the world

## Cynthia Figueroa Guerra

The Max Foundation  
México

*How to contact me:*

[cynthia.figueroa@themaxfoundation.org](mailto:cynthia.figueroa@themaxfoundation.org)



### MY STORY:

When I was studying my degree did community service in an NGO that works with children with cancer; and then knew about MPN, but never in a deep way. After several years working with NGO's and with the pharmaceutical industry, I came to the Max Foundation and it was there where MPN became familiar.

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.



## David Wallace

MPN Cancer Connection  
and PV Reporter  
United States

*How to contact me:*

david@pvreporter.com

704-545-2799

### MY STORY:

I have been a PV patient since 2009. After two emergency room visits in the first week, I quickly learned I would have to become my own advocate.

After going through 5 local hematologists, I finally found a doctor I trust and respect.

- ◆ Created PV Reporter in 2013
- ◆ Established MPN Cancer Connection in 2015

My personal goal is to make a positive impact on the lives of fellow patients.

### ABOUT MY ORGANISATION:

MPN Cancer Connection (MPN-CC) is a patient led 501©3 non-profit organization. It was formed to create awareness that MPN patients are "cancer patients" and should have complete access to local & national programs and benefits.

MPN Cancer Connection provides support services, resources and referrals to help patients manage the on-going emotional and financial challenges of living with a chronic cancer.

PV Reporter was created to provide "easy access" to pertinent information and first hand tips on managing life with an MPN.

PV Reporter and MPN-CC serve a worldwide community.

## Dieter Wenzel

Mpn-netzwerk e.V.  
Germany

*How to contact me:*

d.wenzel@mpn-netzwerk.de



### MY STORY:

ET-diagnosed in 1999, my mpn changed into a myelofibrosis. Only treated with HU and ASS in 2007 the MF developed into an acute leukemia. Because of that I got a stemcell transplantation in May 2008. I spent only 21 days in hospital and after 6 month I could finish every medication. Since this days I'm disease-free.

1999 only a few was known about mpn (it was called „the forgotten disease“) so I tried to learn everything about this exciting disease and wrote 3 brochures (ET/PV/MF) for the patients, mainly for our members. Based on my knowledge 2011 I was called as a patient-representative for the german HTA (<https://www.g-ba.de/english/> G-BA= The Federal Joint Committee) to asses the additional benefit of Ruxolitinib for mpn-patients. In the following years I moved up to be the patient-representative spokesperson in the HTA (responsible for every in europe approved drug of any disease). Meanwhile I'm called as a patient-representative to the Federal Ministry of Education and Research in Germany to judge grants for patientrelevant studys, too.

Thanks to the MPN I could start a new career as a „professional patient“ and gave my life a new turn. Even 13 years after my transplantation I'm still a member of the mpn-netzwerk to bring my experiences to other patients.

### ABOUT MY ORGANISATION:

The German mpn-netzwerk e.V. is the biggest german-speaking non profit advocacy group for mpn diagnosed patients and their relatives.

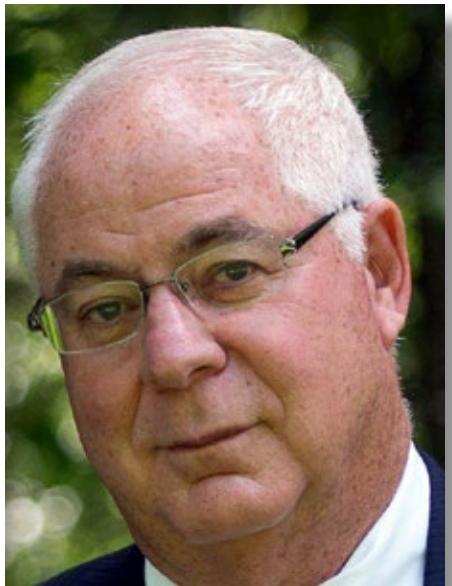
Started as a „yahoo-group“ initiated by only one female patient in 1999 the network was founded 2005 by just a few people. Currently we have nearly 1000 members mainly from Germany, but also from Austria and Switzerland and german speaking patients from all over the world, as well..

Our network is running a website and a bulletin board, the first source of new information for most members. 3 brochures, ET, PV and PMF will send on request to patient as well as to surgeries and hospitals.

Regional meetings are hold on more than 15 places in Germany frequently 1 to 4 times a year. Additional, we have an annual meeting over weekend with presentations and special interest groups with about 200 members and relatives.

It is important for us to be independent from pharma subventions and we are proud about never get money from big-pharma in the past. For doing our work in germany we can apply money from the insurance for special projects and conferences.

We work close together with the German Study Group for Myeloproliferativ Neoplasms (GSG\_MPN).



## Dov Lidor

### The Canadian MPN Network (CMPNN) Patient Advocacy Canada

*How to contact me:*

dov.lidor@canadianMPNnetwork.ca

lidordov@gmail.com

1-416-818-1248

#### **MY STORY:**

Care Partner to Marilyn Lidor (Post-ET Myelofibrosis Patient)

Dov was born and raised in Israel.

In 1975, Dov moved with his wife Marilyn to Canada and embarked on a career in the Canadian Automotive Aftermarket Industry where he held several senior executive positions.

In 2013 Dov formed his own company representing Far East Automotive manufacturers to the North American Automotive Aftermarket Industry.

Dov serves as Vice-chairperson of the Canadian MPN Network (CMPNN) Patient Advocacy.

Dov also volunteers as a Museum educator at the Toronto Holocaust Museum.

#### **ABOUT MY ORGANISATION:**

**The Canadian MPN Network (CMPNN) Patient Advocacy** supports those Patients who have been diagnosed with an MPN (Myeloproliferative Neoplasm) living in Canada, as well as their Care Partners, family members and the medical professionals treating them. On a national level, actively solicit and advocate to Canadian regulatory government bodies, as well as private medical and insurance companies, for the approval and implementation of new and off-label drugs and procedures for the betterment & wellbeing of our MPNN community.

**On a national level**, actively promote education that provides factual and relevant information on MPN's and that increases knowledge and practical support via conferences, websites, electronic data and paper communication. Facilitate member-to-member interaction for increased support and communication. Host an annual CMPNN Conference for the benefit of Patients, Care Partners & family members in a manner that reaches the most people in the most efficient manner.

**On a provincial level**, support and promote local/regional CMPNN Support Groups by facilitating communication from all facets of our CMPNN organization, including actively implementing our Mission Statement and Objectives, and by continually expanding our membership base accordingly.

**On an international level**, attend conferences, webinars and other meetings to promote our CMPNN community, as well as to gain international knowledge that can be subsequently shared with our membership base

## Dražen Vinček

**Croatian Leukemia and Lymphoma Society – Hrvatska udruga leukemija i limfomi - HULLCROATIA ([www.hull.hr](http://www.hull.hr))  
CROATIA**

### *How to contact me:*

[dvincek.hull@gmail.com](mailto:dvincek.hull@gmail.com)

[udruga.hull.zagreb@gmail.com](mailto:udruga.hull.zagreb@gmail.com)

00385 91 4873 561

00385 98 310 488

[www.hull.hr](http://www.hull.hr)



### **MY STORY:**

I was diagnosed with Ph+CML in mid 2010 and was on Glivec until 2014. Now I am taking generic Imatinib.

My results are still good and my illness is in remission.

I am the president of HULL, and the branch office in Varaždin.

### **ABOUT MY ORGANISATION:**

Croatian Leukemia and Lymphoma Society (Hrvatska udruga leukemija i limfomi – HULL) is the leading Croatian society for haematological patients, their families and caretakers. We are providing help, advocacy and support for patients with CML and other haematological diseases.

Our regular activities are:

- Conducting educational campaigns: "With knowledge to health", "I have only one wish", "Make blood cancer visible",
- Marking the days: World Lymphoma Awareness Day, September 15th, World CML Day, September 22th, MDS World Awareness Day, October 25th,
- Monthly educational lectures for patients and general public, Free medical consultations for patients and their families, deals with all the problems that haematological patients meet with,
- Aside from just talking and sharing experiences we organize educational lectures and workshops,
- informing the patients by means of educational booklets, website, Facebook, Twitter and Instagram

Except for Zagreb, which is our main office, we have several branch offices in the country that actively organize educations and other activities for our members (Varaždin, Donji Miholjac, Slavonski Brod, Rijeka, Split and Zadar).



## Erez Rasilevski

“The Flute of Light” Organization  
**Israel**

*How to contact me:*

Erez.rasi@gmail.com

Mobile : +972-54.54.75775

### MY STORY:

I am 45YO, diagnosed with High Risk Myelofibrosis in transition to Acute Myeloid Leukimya (AML) on March 2015. Life expectancy was 6 months. Had Allogenic Stem Cell Transplant (SCT) on June 2015. Currently on daily drugs only, Sport and the sea became my way of life and second nature. I support and encourage other patients to do so as well. It with no doubt helped me get better faster.

### ABOUT MY ORGANISATION:

The Israeli “Flute of Light” Organization is the new home for all types of MPN patients. Flute of Light took upon itself to provide Israeli MPN patients the necessary education regarding their illness, possible treatments, mental support, close support group, medical and handicap rights, constitutional and lobbying activities for approving new drugs and treatments and more.

## Felice Bombaci

Gruppo AIL Pazienti LMC  
Italy

### How to contact me:

[felice.bombaci@ailpazienti.it](mailto: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 abnormal blood tests. Through the Internet I knew a new drug ST1571 (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 ST1571. 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 Malignancies

### 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 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)

email: [infolmc@ailpazienti.it](mailto:infolmc@ailpazienti.it)

Website: <http://www.lmconline.it>



## Fernando Alonso

MPN Spain Association  
Spain

*How to contact me:*  
[tusfacaitu@yahoo.com](mailto:tusfacaitu@yahoo.com)

### MY STORY:

After having a portal thrombotic episode in 2014, I was diagnosed with P.Vera and three years later it progressed to Myelofibrosis.

I made the decision to get involved in taking care of myself,  
research tasks on these diseases, and being led by good MPN specialists.  
Being an advocate patient.  
Well informed patients live longer and better.

### ABOUT MY ORGANISATION:

The MPN Spain Association is recently created (2018). I am part of the Steering Committee and our objectives are to make visible these invisible blood cancers, educating consultants, raising public awareness, advocating for patients and support people with MPNs.

We started with a public page on Facebook, also created a private support group for patients and families in Facebook as well, with great success, in which we present the latest in the MPNs info, webinars with local and international MPNs specialists.

We are improving our Instagram account and also are in Twitter and YouTube, and we are developing a new, more complete, modern and agile website.

We certainly have a long way to go.

## Giampiero Garuti

AIL – MPN Patients' Group  
Italy



### *How to contact me:*

[infommmp@ailpazienti.it](mailto:infommmp@ailpazienti.it)  
+39 06 7038 6012

### **MY STORY:**

My name is Giampiero. I live in a town near Bologna called Castel San Pietro, which I had the pleasure of being the deputy mayor of for 5 years. I'm a father and a grandfather. Before retirement, I used to own a small company. I've been diagnosed with MPN in 2002. In 2013 I received a transplant of haematopoietic stem cell. I'm currently an AIL volunteer and a member of the AIL MPN Patients' Group.

### **ABOUT MY ORGANISATION:**

The AIL MPN Patients' Group (in Italian Gruppo AIL Pazienti MMP Ph-) was founded in 2014 by a small group of patients and caregivers who increasingly gathered a community of people with Myeloproliferative disorders, with the aim of helping patients to cope with their illness and sharing their experience with fellow sufferers.

The Group is entirely made up of patients and caregivers and it has been working from the beginning to spread information and raise awareness of polycythaemia vera, essential thrombocythaemia and idiopathic myelofibrosis, to promote and support research.

Since 2014 we organized 10 patient seminars in several different Italian cities (Milan, Bologna, Rome, Turin, Catania etc.).

As a Patients' Group we took part to previous MPN Horizons and other international patient advocacy activities throughout Europe.



## Giora Sharf

**Israeli Flute of Light Patients Organization  
+ MPN Advocates Network  
+ Israeli CML Patients Organization  
+ CML Advocates Network**

**Israel**

*How to contact me:*

**giora1@inter.net.il**

**Mobile phone: +972-507516690**

### **MY STORY:**

I feel that my personal story reflects on the revolution that CML has gone through in the last 15 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 and do very strict monthly PCR tests, which show that I am still in high 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 400 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 also MPN patients 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 Advocates Network and MPN Advocates Network.

**[www.lepaf.org](http://www.lepaf.org)**

## Hanjun Lee

**KBDCA (Korea Blood Disease & Cancer Association)  
South Korea**

**How to contact me:**

E-mail: [blooddiseasecancer@gmail.com](mailto:blooddiseasecancer@gmail.com)  
phone: +8210-9790-6100Instagram User ID: kbdca



### **MY STORY:**

I'm an assistant administrator of Korea Blood Disease & Cancer Association.

I am responsible for the business of interacting with patient organizations around the world.

Interaction with other patient groups can make a lot of progress for MPN patients.

### **ABOUT MY ORGANISATION:**

Korea Blood Disease & Cancer Association(since 1995) is a nonprofit organization that helps Blood disease and cancer patients to rehabilitate quickly and to go back to their normal life.

KBDCA is contributing to the promotion of health and welfare by carrying out various projects such as financial support, education & counseling programs, information support, and overseas exchange.

We help patients with blood diseases and cancer to be cured promptly and to complete their rehabilitation successfully.



## **Heini Alsio**

**Association of Finnish Cancer Patients**  
**Finland**

*How to contact me:*  
[Heini.alsio@gmail.com](mailto:Heini.alsio@gmail.com)

### **MY STORY:**

I'm a MPN veteran with 17 years experience. I was diagnosed with ET in 2002. It progressed to MF in 2007 but it's very likely I had pre-MF straight from the start. In 2014 I was diagnosed with AML. I'm now 35 and the MF is causing problems more than the AML. I have two healthy kids.

### **ABOUT MY ORGANISATION:**

The Association is for all kinds of cancer. We MPN-patients have a group of our own. We have minor meetings about once a month and a major meeting, seminar, once a year.

Daily we have a good discussion in our Facebook group.

The Association also helps us with information, education, projects etc.



## Ilona Szabo

MPN-Schweiz  
Patientenunterstützungsverein  
Switzerland

### *How to contact me:*

Nifini@hispeed.ch  
+41797522545



### **MY STORY:**

Since December 2016 I have Myelofibrosis, I take only ASS 100.

### **ABOUT MY ORGANISATION:**

I am Member of the board of directors  
MPN-Schweiz. The President is Peter Loeffelhardt



## Inés García González

The Max Foundation  
Latin America

*How to contact me:*

[ines@themaxfoundation.org](mailto:ines@themaxfoundation.org)

### MY STORY:

After working as a volunteer in 2002, I joined officially the organization in 2003. My current position at The Max Foundation is Region Head for Latin America. We work in close contact with local patient groups in the region. Through our program Max Access Solutions we help more than 3,000 patients with access to treatment, access to CML diagnosis and monitoring, information and emotional support.

I am based in Buenos Aires, Argentina.

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries

## Inger Margrethe Landsverk

### Blodkreftforeningen Norway

#### *How to contact me:*

[inger.Landsverk@mimer.no](mailto:inger.Landsverk@mimer.no)  
+4790641331



#### **MY STORY:**

I`m educated as a critical nurse and has been working in the local hospital in Aalesund, my hometown, for many years.

In 2006 I got Polycytemia Vera, and had a major brain stroke.

It took some years to recover and find the best treatment.

In 2011 I participated on MPNVoice`s patient day in London. It gave me a lot of inspiration to work for our group in Norway. In 2015 I became a member of the main board in Blodkreftforeningen and I`m also a buddy for people with PV.

#### **ABOUT MY ORGANISATION:**

The Norwegian blood cancer Association – BLODKREFTFORENINGEN.

We are a nationwide and non-profit organization with approximately 1800 members.

Since Norway has only 5,5 mill. citizens, all different types of blood cancers are members – leukemia, myeloma, MPN, MDS and other rare blood cancers.

Among many local activities, one of our main focus is patient support. We have a patient telephone, we organize workshops, we have various MPN- information and collaborate with various haematological researchs and hematologists.



## Jacqueline Montúfar

The Max Foundation  
Guatemala

*How to contact me:*  
[jacqueline.montufar@themaxfoundation.org](mailto:jacqueline.montufar@themaxfoundation.org)

### 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.

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

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.

## Jana Pelouchová

Diagnóza leukemie, z.s.  
Czech Republic

### How to contact me:

jana.pelouchova@diagnozaleukemie.cz  
+420 728308360



### MY STORY:

Diagnosed chronic myeloid leukemia in 2002, indicated for transplant due to treatment failure but preferred to struggle with different therapies both in clinical trial and with inhibitors that got into clinical practice.

Strongly motivated for patient advocacy, inspired by colleagues from different countries who have built CML support groups. Became co-founder of CML Advocates Network in 2007 and one of the founding trustees of Leukemia Patient Advocates Foundation and active in all networks under the LePAF.

### ABOUT MY ORGANISATION:

Diagnóza leukemie is a patient-governed society providing information, support and advocacy for Czech blood cancer patients except for lymphoma and myeloma, where separate patient groups work in parallel. Formed in 2006 originally as CML patient community, has evolved its activities into a broader scope upon change of its statutes in 2014. Currently serves as a source of education, platform for patients' networking, incorporating caregivers and, improving collaboration with key opinion leaders in each disease area.

International collaboration is a significant feature in the activity, implementing experience from 9 years' Board membership at European Cancer Patient Coalition, Rare Cancers Europe, ECCO Patient Advisory Board, CML, CLL, ALAN and MPN networks, MDS Alliance.

Diagnóza leukemie represents hematology patients at the Patient Advisory Board of the Minister of Health.

[www.diagniza-leukemie.cz](http://www.diagniza-leukemie.cz)

[facebook.com/diagniza.leukemie](https://facebook.com/diagniza.leukemie)



## **Lorna Joanne McKinley**

### Canadian MPN Network Patient Advocacy Canada

*How to contact me:*

Email :- jmcki99425@aol.com  
Phone:- 519 576 1668

#### **MY STORY:**

I was diagnosed in 2012 with PV after my family doctor noticed that my neutrophils were high over a period of a year. I was sent to the local cancer centre to see a hematologist/oncologist. I was tested and found to be JAK2 positive. I also had a high HCT.

I was told that it was a blood cancer but that I probably would not want to research it on the internet. Fortunately I did not take that advice and was able to find a support group ,MPN Ontario from which I learned about my disease. After several years of baby aspirin and phlebotomy I was put on HU. In 2016 I was put on Jakavi as I was intolerant of HU.

#### **ABOUT MY ORGANISATION:**

The Canadian MPN Network Patient Advocacy was formed in 2014 when the Canadian Organization of Rare Diseases brought together a few patients and care givers from across Canada. This group formed the first board of directors with the mission of increasing awareness, educating and supporting people with Essential Thrombocythemia, Polycythemia Vera and Myelofibrosis. At this meeting we also had the opportunity to meet with doctors organization, MPN Canada.

In the four years since the formation of our group, we have under the leadership of our chairperson Cheryl Petruk, been able to bring together patient support groups in Ontario and Vancouver and start groups Alberta and Quebec. We have held a yearly conference in Toronto which includes medical speakers from the Canadian MPN Centre updating patients on the latest research in the field. We also have focused on the whole patient with speakers on living well with an MPN.

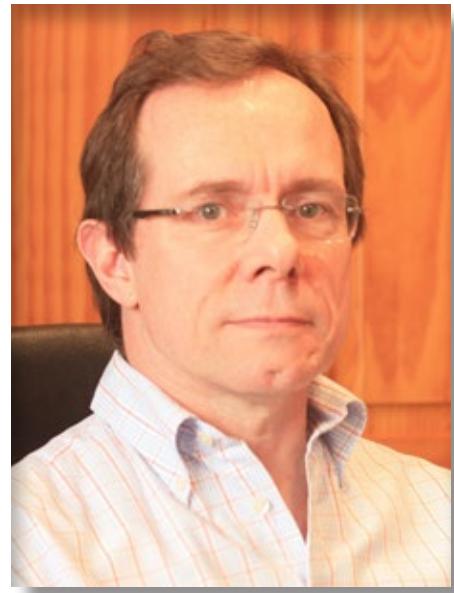
One of the most important things which was started was a Facebook page to which patients are able to access the MPN network and its resources.

## Jon Mathias

**Chairman, MPN Voice**  
**Chairman, MPN Advocates Network**  
**United Kingdom**

**How to contact me:**

[Jon.mathias@iname.com](mailto:Jon.mathias@iname.com)  
+44 7899 945429



### MY STORY:

I was diagnosed with ET in 1998, following a minor stroke.

I was lucky to find myself under the care of Professor Tom Pearson at St Thomas' hospital in London, and subsequently Professor Claire Harrison.

Realising that most patients with MPNs do not have access to such world-class expertise, I helped to found MPN Voice with the aim of providing patients with reliable, up-to-date information and support.

### ABOUT MY ORGANISATION:

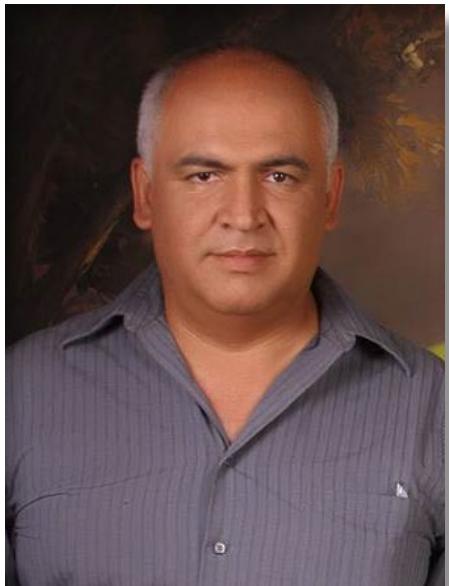
MPN Voice was founded just over 10 years ago to provide information and support to MPN patients in the UK.

Initially we created a website with information about the conditions and treatment options, provided by leading clinicians, primarily Professor Claire Harrison. At that time, we also organised patient meetings in London.

Since then, we have expanded to run patient meetings in many cities around the UK plus a major biannual patients conference attracting the world's leading MPN specialists.

Our website is now in its third iteration and we operate a nationwide 'buddy' system to provide 1:1 patient support.

Our fundraising activities have allowed us to provide seed funding for the world's first study of the epidemiology of MPNs.



## José Luis Castro Aguilar

AGALEMO  
Costa Rica

**How to contact me:**

[jlcastroa@gmail.com](mailto:jlcastroa@gmail.com)  
[www.facebook.com/jlcastroaguilar](http://www.facebook.com/jlcastroaguilar)  
[@jlcastroa & @Agalemo](https://twitter.com/jlcastroa)  
+506-8811 1165 WhatsApp

### MY STORY:

My wife Silvia was diagnosed of CML since 1998 and we have been in a constant struggle ever since. She is now 52, she is the mother of two boys, ages 19 and 12, works as a Librarian and is currently the president of our association. Her treatment involves all the pre-TKI drugs plus Imatinib, Nilotinib and currently with Dasatinib. She has the F359V PH mutation.

Regarding me, I am an Electrical Engineer and I have 6 children, ages 36-30-24-23-19-12.

I am a founding member of AGALEMO and officially I hold the position of the Fundraiser, Scientific affairs and delegate to CML Horizons.

### ABOUT MY ORGANISATION:

AGALEMO was founded in 1998 as a support group to leukemia patients.

We became a legal association by 2005 and we received afterwards a lot of training focused on capacity building and about the scientific background of the disease.

Since the very beginning we realized that our association had to play a different role because the new drugs available for CML was denied to the patients in our country.

We had to fight in order to receive the Imatinib by 2003, then we had to fight again for the introduction of Nilotinib to our country by 2008 and a lot more difficult struggle to make Dasatinib available by March 2012.

CCSS is the healthcare institution providing health services to the whole population. There are no out-of-pocket expenses and CCSS pays the bus ticket and even covers one night hotel if the patient comes from a far place.

In April 1st, 2019 our patients began receiving an Imatinib generic made in Canada and approved by FDA as equivalent to the original branded Imatinib.

AGALEMO welcomes you all to this small country that we call home!

**PURA VIDA!**

## Ken Young

**MPN Alliance Australia**  
**Australia**

### *How to contact me:*

+61-408-341-795  
[info@mpd-oz.org](mailto:info@mpd-oz.org)  
[mpnaa@mpnallianceaustralia.org.au](mailto:mpnaa@mpnallianceaustralia.org.au)



### **MY STORY:**

I was diagnosed with undefined myeloproliferative disorder in April 1998 following a thrombotic event, later confirmed as polycythemia vera. My initial treatment was venesection. In December 2005 my spleen spontaneously ruptured. I then commenced hydroxyurea which quickly failed. In February 2006 I commenced Roferon until January 2019 when I started Pegasys. I established MPD-Oz Email Support List in September 1998 to provide resources for Australian & New Zealand MPN patients, it currently has 279 subscribers. I am a founding member of MPN Alliance Australia. See my presentation at the Melbourne MPN Advocacy & Education International Patient Education event in April 2017.

### **ABOUT MY ORGANISATION:**

MPN Alliance Australia (MPN AA) is a support & advocacy network for MPN patients & carers. MPN AA is a volunteer patient support group affiliated with Leukaemia Foundation of Australia. Currently we are 7 volunteers located across Australia. Since 2014 MPN AA has raised more than AUD\$100,000 for MPN research in major Australian Research Centres. Including in partnership with MPN Research Foundation (MPNRF) to support the MPN Interferon Initiative.

MPN AA has undertaken important advocacy and lobbying activities including:

- National Strategic Action Plan for Blood Cancer.
- Successfully lobbying for Pegasys® to be listed on Pharmaceutical Benefits Scheme
- Submissions to the Senate Committee Inquiry into the Availability of New, Innovative and Specialist Cancer Drugs In Australia.

MPN AA collaborates with other patient organisations including The Leukaemia Foundation, Rare Cancers Australia and Rare Voices Australia in campaigns of awareness raising & supporting patients & carers.



## Kristina Modic

**Slovensko združenje bolnikov z  
limfomom in levkemijo, L&L  
Slovenia**

*How to contact me:*

modic.kristina@gmail.com

+386 31 643 122

<https://www.facebook.com/modic.kristina>

<https://www.instagram.com/kristinamodic>

<https://twitter.com/modickristina>

### MY STORY:

I was diagnosed with non-Hodgkin's Lymphoma (DLBCL) and was successfully cured in 2005. I am a co-founder of Slovenian Lymphoma and Leukemia Patient Assoc., L&L. I was voluntary President from May 2007 till March 2016. From April 2016 I am an Executive Director of the L&L Association, where I am responsible for the development of new and existing programmes for patients, advocacy, awareness campaigns, public relations and for successful operation of the L&L Association.

I am very proud to be one of the key developers of comprehensive rehabilitation programme for blood cancer patients which is provided last 4 years by our L&L Association in a partnership with the Slovenian Society of Haematology and in cooperation with various Slovenian experts from the fields of rehabilitation, hematology, oncology, and other fields of social and health care. A programme for blood cancer patients is first such programme for cancer patients in Slovenia.

Last few years I am also a president of Slovenian association of cancer patient organisations ONKO NET and a vice-president of the Board of patients representatives at Slovenian Institute of Oncology as well as an active member of different project groups on national and international level.

### ABOUT MY ORGANISATION:

Slovenian Lymphoma and Leukemia Patient 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 treatment & care, quality life with the illness & after it. Helping patients and relatives, striving for the promotion of health and healthy lifestyle.

Key projects/activities of L&L: publishing/distributing info materials, individual and group meetings, 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](http://www.limfom-levkemija.org), [www.najboljsanovica.si](http://www.najboljsanovica.si)  
e-mail: [limfom.levkemija@gmail.com](mailto:limfom.levkemija@gmail.com)

Facebook page SKUPAJ NA POTI DO ZDRAVJA

## Leonard van Egmond

MPN Stichting  
The Netherlands

### How to contact me:

[leonard@mpn-stichting.nl](mailto:leonard@mpn-stichting.nl)  
+31 653 822 896



### MY STORY:

Beginning of 2013 I was struck by an cardiac infarction, and 6 months later by a severe gastro-intestinal bleeding.

After that I was diagnosed with PV, having a JAK2 mutation.

I have been treated with Hydroxy-Urea, and PEG-interferon-a, but got an allergic reaction on both treatments. I now take Ruxolitinib for over 5 years, and reasonably stable, with low Ht and Hb, and high Thrombocyte counts.

I have a medical education and 35 years experience in different Pharmaceutical companies.

I'm a Board member of the MPN Stichting since the end of 2018.

### ABOUT MY ORGANISATION:

The 'MPN-Stichting' (Dutch MPN foundation) is an organization that provides its members with information about MPN, medication, treatment options, etc.

The 'MPN-Stichting' promotes and creates opportunities for contact with fellow patients in various ways. By telephone, by internet forum, by its own magazine Pur Sang, by an annual meeting for all members. And there is a private Facebook group.

The 'MPN-Stichting' has contacts with medical specialists, pharmaceutical companies, other patient-organizations and is supported by a medical advisory board of MPN specialists.

The "MPN-Stichting" was founded in 2003. It is a voluntary organisation that receives subsidy from the Dutch government. There are 1200 members.

## MINI VIRTUAL CONFERENCE



# Lidija Pecova

## CML Advocates Network

## HEMA

### *How to contact me:*

Email: [lidijs@cmladvocates.net](mailto:lidijs@cmladvocates.net)

Mobile: +389 7838 8235 (WhatsApp, Viber & Telegraph)

Facebook: Lidija Pecova

Twitter: @lidijspecov

Instagram: lidijapecova

LinkedIn: Lidija Pecova

### **MY STORY:**

Prior to relocating to my birth town of Skopje in December 2014, I lived most of my life in Australia and worked in business management and I was involved in the non-for-profit sector in mental health. After having a break I wanted to be able to use my corporate and non for profit experience from Australia and give back to my community and found myself working with a Cancer Patient Organization and through this work I met Giora and Jan and had the great fortune of joining their team. Through my experience in Australia and LePAF, I formed HEMA – Macedonia's, association for help and support of patients and caregivers of Hematology Diseases. I am passionate about helping people and would like to be a part of a real movement and be able to give back to my community through my combined experiences.

### **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 hematological diseases and support for caregivers by strengthening patient advocacy in this area.

It aims 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 and provide our patients with current therapies and better quality of life.

HEMA is committed to increasing public understanding of hematological diseases and providing access to latest treatments, information and resources as well as dedicated social communities where individuals impacted by these conditions can share information, support and inspiration throughout the year.

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.

## Lise-lott Eriksson

Swedish Blood Cancer Association  
Sweden

*How to contact me:*



### MY STORY:

I started my work as a patient advocate for the Swedish Blood Cancer association after being diagnosed with ET in 2011 after a thyroid gland surgery. Two years earlier my father was diagnosed with multiple myeloma. I'm now treated with interferon Pegasys every 4 weeks and ASA.

When not involved in the Swedish Blood Cancer association I work for our family business in the building construction industry

### ABOUT MY ORGANISATION:

The main task of the Swedish Blood Cancer Association (Blodcancerförbundet) is to support those affected by blood cancer as well as their caregivers/relatives and haematological personnel. The association was founded in 1982 with the main goal that everyone with a blood cancer disease should be offered good and equivalent treatment/rehabilitation independent of where in the country they live, to spread knowledge about blood cancer as well as raise money for research. To reach these goals we for example lobby against politicians, hand out medical booklets about the diseases we represent, arrange membership meetings, offer "peer-to-peer buddies" to patients/relatives and have a membership magazine (Haema).

The Swedish Blood Cancer Association has its central office in Stockholm and consists of 14 local associations in all parts of the country. The local associations keep contact with regional hospitals and some of them also have economic funds that make it possible for members and nursing staff to apply for economic support. Additional expenses for patients with illness are supported locally and our local associations also offer support for those who recently have received a diagnosis and their families. Nationally a network is formed to continually train and assist these dedicated people who work pro-bono.

The Swedish Blood Cancer Association is a non-profit organization partially supported by the Swedish state through governmental funding. Internationally we are a member of various international organizations. We also have close relationships with other Nordic blood cancer associations and are active members of the umbrella organization The Network Against Cancer in Sweden. All in all we see ourselves as the "voice of the patient" and work strategically, long-term as well as dedicated to meet the specific needs of our approximately 4000 members.



## Lyat Granati Espinosa

The Max Foundation  
Chile

*How to contact me:*

[lyat.granati@themaxfoundation.org](mailto:lyat.granati@themaxfoundation.org)  
(56-9) 84287181

### MY STORY:

I work with The Max Foundation as the Local Program Coordinator for Chile since 2015, and work with MPN patients in Chile through a program titled Day by Day. This was my first approach to this diagnosis and the first time that I met patients under treatment for this kind of disease.

My role in the program is to help patients with emotional support through phone calls, provide them with educational materials and updates on current treatments, coaching in treatment adherence and treatment follow-up. They also can take part in patients meetings organized by the program.

I have a psychology background

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.

## Maja Kocic

Lymphoma Patients' Association LYPA  
Serbia

*How to contact me:*

majaklipa@gmail.com



### MY STORY:

My name is Maja Kocic, I am a President of LYPA. I am a member of several other regional and international organizations. I earned my M.Sc. in Electronic Engineering at the University of Nis, Serbia. After graduation I was working as a teaching assistant.

In 2003, I was diagnosed with DLBCL, stage IV and went through chemo, radiation therapy and biological therapy. After all therapies I needed a bone marrow

transplant that had at the end of 2004. After my recovery, I joined LYPA and have been active patient advocate ever since. I was a member of Lymphoma Coalition Board of Directors.

### ABOUT MY ORGANISATION:

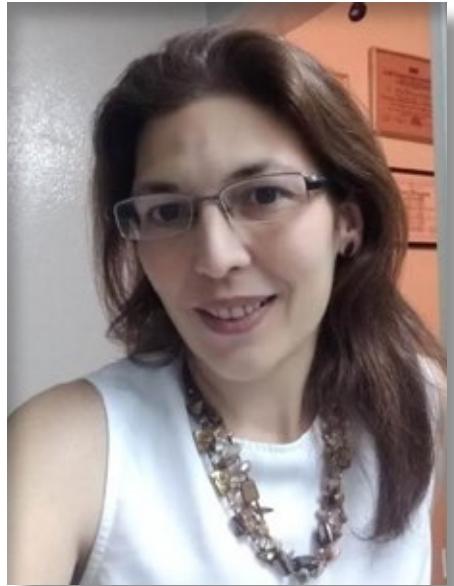
Lymphoma Patients' Association LYPA is Serbian Organization for lymphoma patients, family members and friends.

LYPA will continue to be the leading national Lymphoma patient association and we will try to improve the quality of life of lymphoma patient

Our objectives are: raising the level of knowledge about lymphoma, giving information to the patients and supporting them as well, advocating the rights of the lymphoma patients, providing a better access to new treatments and clinical trials and promoting a healthy way of living.

By providing high-quality information, organizing meeting, lectures and training events and sharing the inspirational story of our survivorship we encourage, motivate and inspire not only lymphoma patients but also every audience. My team have implemented and managed a great number of successful social and educational campaigns in the field of lymphoma awareness, access to innovative treatment and lymphoma patient nutrition.

We believe in the power of kindness, knowledge and responsibility for achieving great goals.



## Maria Julia Sanchez

The Max Foundation  
Venezuela

*How to contact me:*

[maria.sanchez@themaxfoundation.org](mailto:maria.sanchez@themaxfoundation.org)

### MY STORY:

I have been working for the foundation since September 2018 supporting CML and Gist patients who need access to treatment and support. During this time I have had the opportunity to meet and support wonderful people, as well as learn from them every day.

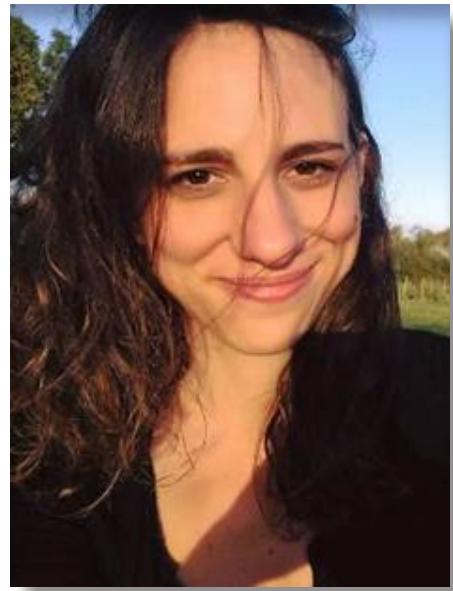
### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.

## María Victoria Duhalde

The Max Foundation  
Argentina



### *How to contact me:*

[Victoria.Duhalde@themaxfoundation.org](mailto:Victoria.Duhalde@themaxfoundation.org)  
+54 9 11 57089785

### **MY STORY:**

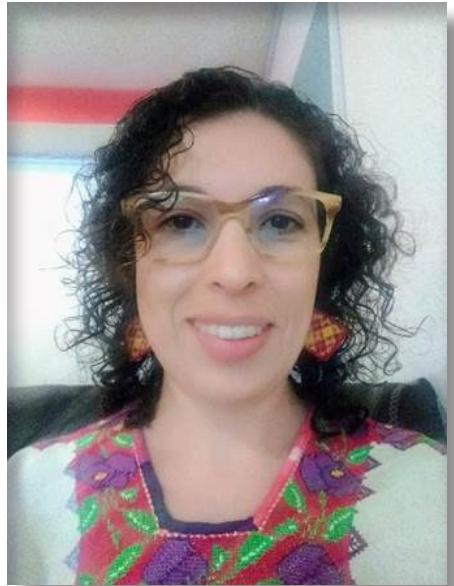
I'm a psychologist living in Buenos Aires, Argentina.

I worked in The Max Foundation as a local coordinator Program of Argentina, Perú and Ecuador since 2012.

### **ABOUT MY ORGANISATION:**

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.



## Mariana Rubi Gonzalez

The Max Foundation  
Mexico

*How to contact me:*

[mariana.rubi@themaxfoundation.org](mailto:mariana.rubi@themaxfoundation.org)

### MY STORY:

15 years ago, just finishing my degree, I was searching for a meaningful job; a friend told me about this organization; I had no idea what CML was; but I fell immediately with the work they were doing. So I started this path of studying, meeting people, understanding the process.

During this time; I have been very involved with many of our patients; working not only as an advocate but interested in their emotional health (I'm a Psychologist).

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.

## Martha Rosario

The Max Foundation  
Dominican Republic



### *How to contact me:*

[martha.rosario@themaxfoundation.org](mailto:martha.rosario@themaxfoundation.org)  
Cel. 1-809-729-7219  
Instagram:martharosario19

### **MY STORY:**

I am Dominican, married with a daughter and a Clinical Psychologist by profession, I have been working in the health sector for 20 years specifically in the area of oncology, in 2003 I began to work as a volunteer at the Max Foundation and in 2007 I began to work as a local coordinator for República The Dominican Republic and Haiti, throughout my time at Max, I have met wonderful people who have taught me the true value of life and that despite adversity we must continue to fight and I am proud to belong to an organization like Max where it important is that the patient feels that there is always hope.

### **ABOUT MY ORGANISATION:**

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.



## Marianne Meijer

MPN Stichting  
The Netherlands

*How to contact me:*

Marianne@mpn-stichting.nl  
+31365296158/+31640006320

### MY STORY:

I was diagnosed with Essential thrombocythemia in 1991. I was 38 years old and now I am 65 and doing well. About the years I learned a lot about MPN's. There was not any information at all in 1991. The first 15 years I was on aspirin only, then my red bloodcells became too low and I had to take EPO. Since 2 years I am treated with 0.45 mcg Pegasys every 3 weeks. I have the Calr2 mutation and my blood counts are stable. Now I can reduce the EPO and I hope that the fibrosis in my blood will also be discrease. Thanks to all new developments the future looks better then my doctor told me in 1991.

### ABOUT MY ORGANISATION:

The Dutch MPN foundation was founded in 2003. It is a non-profit organization for patients with Myeloproliferative disorders. There are 1,200 members. The foundation supports, informs and represents these patients. We publish a magazine 3 times a year, we distribute patient brochures and organize meetings for patients and their loved ones. There is also a telephone consultation hour. The foundation promotes contact with fellow patients in various ways. We are supported by a medical advisory board of MPN specialists. There are also good contacts with other related patient organizations. We try to organize more together in the near future, especially in contacts with and with pharmaceuticals and insurers. There is also a website ([www.mpn-stichting.nl](http://www.mpn-stichting.nl)) and a patient forum ([www.stichtingmpn.nl](http://www.stichtingmpn.nl)) where patients support each other and there is a private facebook group. The foundation is a voluntary organization and receives subsidy from the Dutch government. This year we celebrate our 15th anniversary.

## Massimiliano Donato

Gruppo AIL Pazienti MMP Ph  
Italia

### *How to contact me:*

[donato.massimiliano@gmail.com](mailto:donato.massimiliano@gmail.com)  
[ailpazienti@ail.it](mailto:ailpazienti@ail.it)



### **MY STORY:**

I am Massimiliano Donato, a founding member and the current head of the AIL MPN Patient Group. I am happily married to Maria Rosaria and I am father of two wonderful daughters, Paola, 15 years old, and Elena 10 years old. I work in a bank as an Asset Manager and I live in Calabria in the city of Rosarno. From 2005 I've been living with ET and I am following a drug therapy. Meanwhile I try to enjoy life as much as possible, because following the slogan of my group, "I don't only want to ask for more days to life, but also more life to days"

### **ABOUT MY ORGANISATION:**

Gruppo AIL Pazienti MMP Ph-

The AIL MPN Patient Group (called Gruppo AIL Pazienti MMP Ph-) was founded in 2014 by a small group of patients and caregivers who increasingly gathered a community of people with Myeloproliferative disorders, with the aim of helping patients to cope with their illness and sharing their experience with fellow sufferers. The Group is entirely made up by patients and caregivers and it has been working from the beginning to spread information and raise awareness of polycythaemia vera, essential thrombocythaemia and idiopathic myelofibrosis, to promote and support research.

Both in 2014 and 2015 the Group organized three seminars in different Italian cities:

2014

January in Rome

November in Varese

November in Reggio Calabria

2015

May in Catania

November in Bologna

December in Rome



## **Matti Santalahti**

**Association of Finnish Cancer Patients**  
**Finland**

*How to contact me:*

[mattikalervo.santalahti@elisanet.fi](mailto:mattikalervo.santalahti@elisanet.fi)  
+358 50 5722 365

### **MY STORY:**

I have the ET. I am 69 years old. The diagnosis with its medication stopped my problems that I had had a couple of years: Thrombosis, deep vein thrombosis, vein thrombosis...

### **ABOUT MY ORGANISATION:**

The Association is for all kinds of cancer. We MPN-patients have a group of our own. We have minor meetings about once a month and a major meeting, seminar, once a year.

Daily we have a good discussion in our Facebook group.

The Association also helps us with information, education, projects etc.

## Maz Campbell-Drew

**MPN Voice**  
**England**

**How to contact me:**

[maz.cd@mpnvoice.org.uk](mailto:maz.cd@mpnvoice.org.uk)  
07934689354



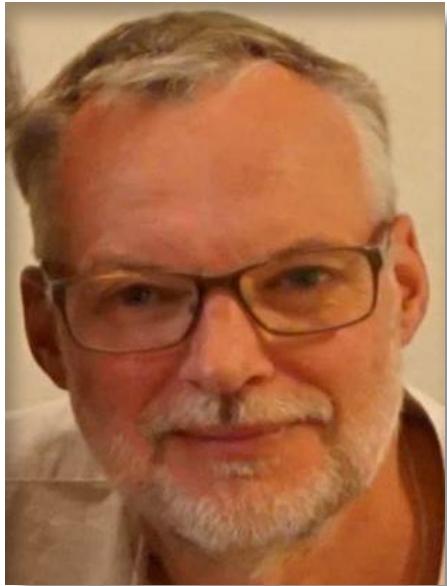
### **MY STORY:**

I was diagnosed with ET in 2003, it came as a huge shock to me, but I was reassured that my life was not about to end. In 2008 I joined MPN Voice as the Administrator.

Helping people with MPNs has had an extremely positive effect on me, I have learnt so much over the years from patients and experts, and I now enjoy my life to the full and let my ET live with me, rather than me living with it.

### **ABOUT MY ORGANISATION:**

MPN Voice's mission is to provide clear and accurate information and emotional support to everyone who has been diagnosed with a myeloproliferative neoplasm (MPN) and their families/friends. MPN Voice has members across the UK and in many other countries throughout the world. We offer a website, annual patients' forums around the UK, and a Peer Support programme to allow people with MPNs to contact others in similar circumstances. We also have an online forum at HealthUnlocked which is a supportive and informative online forum where you can ask questions about anything related to MPNs, and get replies from people who really understand you - people living with a MPN. In addition we produce information leaflets and a newsletter for people with MPNs so that patients are better informed and have more confidence dealing with the management of their condition. MPN Voice also raises money to fund research towards a cure and advocacy for patients. Most of all we aim to offer hope to everyone who has a myeloproliferative neoplasm.



## Meinard Wendelaar Bonga

MPN stichting  
The Netherlands

*How to contact me:*

[meinard@mpn-stichting.nl](mailto:meinard@mpn-stichting.nl)  
+31 6 53 404 899

### MY STORY:

At the end of 2013, I was struck by a sudden hemorrhage in my esophagus caused by esophageal varices. The cause turned out to be a thrombosis of the vena porta. Several operations were carried out, one of them went wrong. Result was a violent bleeding, causing pulmonary embolism and ischemic cerebral vascular incidents.

Finally I was diagnosed ET, JAK2. The number of platelets is still low and fairly stable.

I am a volunteer of the MPN-Stichting since 2016 and became a Board member in 2017.

### ABOUT MY ORGANISATION:

The 'MPN-Stichting' (Dutch MPN foundation) is an organization that provides its members with information about MPN, medication, treatment options, etc.

The 'MPN-Stichting' promotes and creates opportunities for contact with fellow patients in various ways. By telephone, by internet forum, by its own magazine Pur Sang, by an annual meeting for all members. And there is a private facebook group.

The 'MPN-Stichting' has contacts with medical specialists, with pharmaceuticals, with other patient-organizations and is supported by a medical advisory board of MPN specialists.

The "MPN-Stichting" was founded in 2003. It is a voluntary organisation that receives subsidy from the Dutch government. There are 1200 members.

## Melisa Gisele Fazio

The Max Foundation  
Argentina

### *How to contact me:*

[melisa.fazio@themaxfoundation.org](mailto:melisa.fazio@themaxfoundation.org)  
(54) 911-23509765



### **MY STORY:**

I am a social worker and I work at The Max Foundation since 2015, as a Local Program Coordinator for Argentina, Bolivia y Paraguay.

My role in the program is to manage treatment access programs in these countries, and provide support to patients.

### **ABOUT MY ORGANISATION:**

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.



## Mercedes Arteaga

The Max Foundation  
Argentina

*How to contact me:*  
[mercedes.arteaga@themaxfoundation.org](mailto:mercedes.arteaga@themaxfoundation.org)

### MY STORY:

After a few years of helping The Max Foundation as a volunteer, I started working officially in 2009. Since then, I have been in close contact with local patient associations, first in the southernmost countries and later in the whole Latin America region.

Currently I am working as Program Officer for the Latin America region and oversee the Max Access Solutions program for over 3000 patients in 19 countries.

I am based in Buenos Aires and have a psychology background.

### ABOUT MY ORGANISATION:

The Max Foundation is a global health non-profit organization that believes that all people living with cancer have the right to access the best treatment and support. Through personalized access services, quality training and education, and global advocacy efforts, we aim to help people face cancer with dignity and hope.

Our services are global and multifaceted. We provide education and training at all levels of the communities in which we work. By partnering with industry, government agencies, health care providers, and national cancer patient organizations, we are able to support people and provide effective solutions for access to treatment. Through our global advocacy efforts, we work to raise awareness of the disease and draw attention to the needs of people living with cancer. Every year, our dedicated team helps people in more than 100 countries.

## Michelle Woehrle, MPA

MPN Research Foundation  
USA

### *How to contact me:*

708-703-0807  
mwoehrle@mpnrf.org



### **MY STORY:**

I am formerly the Executive Director of MPN Research Foundation. I continue to work with their new E.D. Kapila Viges on specific projects such as the Patient-Focused Drug Development advocacy work and anything they need. I live in the suburbs of Chicago with my husband Andrew and my two little boys, Baron and Isaac. I came to work at MPNRF in 2007 at which point I met Bob Rosen. He was the first person I met who was living with an MPN, but that soon changed. I have met, befriended and worked with and for thousands of people living with an MPN.

### **ABOUT MY ORGANISATION:**

IMPNRF is celebrating its 20th anniversary beginning in December 2020. When Bob Rosen and others with MPN founded MPNRF the focus was on funding research. Most of the founding members have passed away but the organization lives on to be there for people diagnosed with MPN who are waiting for answers and more therapeutic options. better therapies.

The board of directors of MPNRF are all people with an MPN, their friends and family. MPNRF has invested \$15 million and growing in scientific projects that seek to impact the lives of people with an MPN. This includes a 3 year initiative - the IFN Initiative - which invests \$1.5 million over 3 years into a global consortium of laboratories who routinely communicate about their projects and jointly seek to solve problems. The goal: understand why IFN works against MPN, why it works for some patients but not others, and how to ensure these questions are answered so that all patients and the scientific community can better understand the disease.



## Milica Kuzmanovska

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

**How to contact me:**

[milica@hema.org.mk](mailto:milica@hema.org.mk)

+38970349550

### **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 biggest 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.

## Mirjana Babamova

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

**Macedonia**

### **How to contact me:**

[mirjana.hema@gmail.com](mailto:mirjana.hema@gmail.com)

+38978397704



### **MY STORY:**

I am a graduated dentist from the University St. Cyril and Methodius, Skopje and beside dentistry I have managed to build professional experience in non-for-profit patient organizations. Patient advocacy is my main area of interest and I have been working directly with patients and physicians for 11 years, mainly focused on solid tumors and melanoma in the past. Since 2018 I have joined HEMA - Association for support of patients and caregivers of Hematology diseases as the Executive Manager and a patient advocate.

### **ABOUT MY ORGANISATION:**

Association HEMA Skopje is a voluntary, non-profit, non-governmental, non-partisan organization established with free association of citizens in order to offer support and information to patients, caregivers and families affected by hematological diseases, to lobby these patient to enable and to have better and equal access of quality and modern therapy and treatment. Through campaigns and other activities HEMA would improve patients quality of life as well as raise awareness of hematological diseases.

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 malignances . HEMA is actively working on strengthening patient knowledge about their disease, treatment options, how treatment and care should be proved and their rights as patients.



## Moti Levy

**Halil Haor- Flute of LightHome  
of blood cancer patients  
Israel**

*How to contact me:*

[imotilevy@gmail.com](mailto:imotilevy@gmail.com)

972533529999

### **MY STORY:**

I was diagnosed with p.v at the age of 37 (in 2005).

In the first years I've been treated with blood clots, and for the last three years I've been treated with Interferon peg.

My Drs now recommend that I start treatment with Jakavi but as it is not reimbursed in my country, I can't get an access to the drug.

### **ABOUT MY ORGANISATION:**

Flute of light or in Hebrew- Halil Haor, is the blood cancer patients organization in Israel. It was created by our founder, Giora Sharf, in 2011 to give an address to the 30'000 blood cancer patients living in Israel.

The organization goals and activities include:

1. Patients empowerment through many face to face meetings in various hospitals in Israel and patients educational material
2. Supporting the patients who are facing psychological challenges by a trained mentoring network and patients forums
3. Supporting research and developing PRO tools to better understand and serve patients needs
4. Fighting for patients engagement in our HTA system and bringing the patients voice to every place it needs to be heard

## Param Puthen

### Friends of Max India

*How to contact me:*

param\_psp@yahoo.co.in

+91 9663078002

+91 9538895673



#### **MY STORY:**

Parameswaran P S, Param, am a trustee with Friends of Max. I represent the states of Karnataka and Kerala city Chapters from the south region of India. I am a Survivor of CML and underwent Bone Marrow Transplant in November 2006, and I share my testimony as a part of Share and Learn in various cancer awareness programs. I Volunteer for various cancer care activities in my region.

#### **ABOUT MY ORGANISATION:**

Website of your organization: [www.friendsofmax.info](http://www.friendsofmax.info)

Services of your organization: Friends of Max is a CML & GIST support group for survivors and caregivers. It was formed in 2003 as the support group arm of the Max Foundation. Need was felt for a support group with the increasing number of cases that were being reported every month. Slowly and steadily, Friends of Max has today grown to become the largest support group for Cancer survivors run by Survivors in India

Members are reached through our regular outreach program with sharing of Information, educating them on importance of compliance and giving moral and emotional support. Outreach meetings are held across the length and breadth of the country. We also have an Annual Leadership Summit of our City Chapter leaders, where they are empowered with latest updates & information.

FOM India will be taking lead to establish the MPN support group from India thereby improve the Quality of Life for MPN patients and their care givers



## Pasusant Wattanaboonya

MPN Patient Advocacy Group  
Thailand

*How to contact me:*

Email: [pasusant63@gmail.com](mailto:pasusant63@gmail.com)  
Mobile: 66891786867

### MY STORY:

I am a 21-year CML survivor. After I had received the contact from Mr. Peter Loffelhardt of MPN Advocates Network requesting to expand the support to Thailand, I decided to use my experiences to help another group of patients living with MPN and founded the first MPN Patient Advocacy Group in Thailand in 2018 with a crystal clear vision of enhancing both knowledge of MPN and Quality of Life for MPN patients in Thailand.

### ABOUT MY ORGANISATION:

MPN Patient Advocacy Group Thailand has just been established in 2018 with a close group of about 40 ET patients under the consultancy of the Thai MPN Working Group chaired by Assistant Professor Noppadol Siritanaratkul who is MD Division of Hematology Dept. of Medicine Faculty of Siriraj Hospital.

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

We have created FB Page of our group @mpnthailand , official website :

[www.mpnthailand.com](http://www.mpnthailand.com) and Line's member room for day-to-day discussion and information sharing.

## Peter Loffelhardt

**Asociación de Afectados Neoplasias  
Mieloproliferativas (MPN España) and  
MPN Patientenunterstützungsverein  
Switzerland**

**How to contact me:**

pelo.globe@gmail.com

0034 629 444 393

0041 76 394 11 08



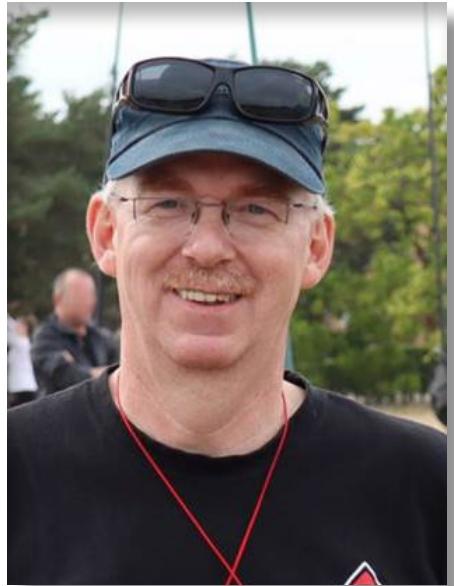
### **MY STORY:**

I am 75 years old, Swiss nationality, living in Barcelona. Around 26 years ago I have been diagnosed with PV and during many years I kept the illness under control with Aspirin and Phlebotomias. Since around 7 years I am on Hydroxyurea and so far, besides a very large spleen, all is under control and I can enjoy a normal life style (touch wood).

Since I am retired I am very much involved in PAG work and with lots of international contacts.

### **ABOUT MY ORGANISATION:**

The two Groups in Spain and Switzerland are taking care of MPN patients in both countries. Regular Patients meetings are held, nowadays virtual, with the participation of national and international Professors, discussing various aspects of the different aspects of our illness. In our Facebook group and other social medias we are presenting different articles and videos appearing all around the world and the most important ones are being translated into native language. The actual virtual times, have opened a lot of new doors to communicate with patient advocacy world.



## Rainer Kuhlmann

Mpn-netzwerk e.V.  
Germany

*How to contact me:*

r.kuhlmann@mpn-netzwerk.de  
Phone: +49 160 901 903 27

### MY STORY:

The day of my diagnosis of ET in 2003., I joined the German Yahoo Group mpn-netzwerk. 2 years later in 2005. we found the registered association mpn-netzwerk e.V. with only 10 people and I worked 10 years in the board.

2015. I started to work as the Admin for the Bulletin Board, the website and all other digital communication in our association, still close to the board.

ET changed to PMF meanwhile, but with a CARL+ and TET2 mutation. I still have little trouble without the constant fatigue.

### ABOUT MY ORGANISATION:

The German mpn-netzwerk e.V. is a non profit advocacy group for mpn diagnosed patients and their relatives.

Founded 2005. with only 10 people we are 850 members in 2019. manly from Germany, but also from Austria and Switzerland.

Our network is running a website and a bulletin board, the first source of new information for most members.

3 brochures, ET, PV and PMF will send on request to patient as well as to surgeries and hospitals.

Regional meetings are hold on more than 15 places in Germany frequently 1 to 4 times a year. Additional, we have and an annual meeting over weekend with presentations and special interest groups with about 200 members and relatives.

The mpn-netzwerk e.V. is independent from pharma subventions, because of the German national health insurance system. We can apply money from the insurance for special projects and conferences.

We work close together with the German Study Group for Myeloproliferativ Neoplasms (GSG\_MPN).

## Rick Winneker, PhD

MPN Research Foundation  
USA

### How to contact me:

914-217-7209

rwinneker@mpnrf.org



### MY STORY:

I am a former research scientist having spent over 20 years working in pharma R&D. In 2010, I joined the Leukemia & Lymphoma as their head of research. My son is a leukemia survivor so I had first hand knowledge of the importance of research. I have had a long working relationship with the MPNRF and in 2018 joined their staff as the Director, Strategies and Research Operations. My focus is on the research funding side of the organization but greatly appreciate their important patient education and advocacy efforts. I look forward to my first MPN Horizons Conference

### ABOUT MY ORGANISATION:

The MPNRF is celebrating its 20th anniversary beginning in December 2020. When Bob Rosen and others with MPN founded MPNRF the focus was on funding research. Most of the founding members have passed away but the organization lives on for people diagnosed with MPN who are waiting for answers and more therapeutic options.

The board of directors of MPNRF are mostly people with an MPN, their friends and family. MPNRF has invested \$15 million and growing in scientific projects that seek to impact the lives of people with an MPN. This includes a 3 year initiative - The IFN Initiative - which invests \$1.5 million over 3 years into a global consortium of laboratories who routinely communicate their progress and jointly seek to understand why IFN works for some patients but not others, and how to enhance its activity. This year, we launched a new initiative dedicated to halting MPN disease progression. Our goal is to establish a network of research investigators who will work collaboratively to address fundamental knowledge gaps and develop intervention strategies to halt disease progression.



## Robert Zelig

Israeli Flute of Light Patient's Organization  
+ MPN Advocates Network  
Israel

*How to contact me:*

[fridarobi@gmail.com](mailto:fridarobi@gmail.com)

Mobile phone- +972-528905817

### MY STORY:

As a routine, I perform a yearly laboratory survey and ultrasound of the stomach cavity. During the test of 2009 my general Practitioner informed me that I have an enlarged spleen. In the first quarter of 2013 my leucocyte and some other parameters were beyond the limits. Two years earlier, I was exposed to a Pruritus attack that I attributed it to insect bites, but my Dermatologist suspected that it may be attributed to some blood disorders. My General Practitioner directed me to a Haematologist and I passed the JAK 2 Test followed by Bone Marrow biopsy and I was finally diagnosed as suffering from PMF.

### ABOUT MY ORGANISATION:

When I was diagnosed in 2013 as suffering from Primary Myelofibrosis PMF, I tried to contact an organization that is familiar with this rare disease and can provide some support. I was deeply disappointed that is no such an organization, and then I observed the CML Patient's Organization founded and conducted by Giora Sharf and I made contact with him. IN 2014 Giora decided to expand the activities to other blood cancers patients and the Flute of Light was founded. This organization provides support for the MPN patients all over the country. The main activities of this organization is by holding many MPN meetings in different location of Israel in order to educate the patients, to keep permanent contact, to provide booklets and videos that describes the different disease journey for PV, ET and PMF. In 2015 with Giora's support the MPN Advocates Network was established and the expectations are that MPN patients shall gain a great benefit from the support provided from this Non Profit organization.

## Ruben A. Mesa, MD

**Director**  
**Mays Cancer Center at UT Health**  
**San Antonio MD Anderson**  
**San Antonio, TX, USA**

**How to contact me:**

Ruben Mesa, MD  
[mesar@uthscsa.edu](mailto:mesar@uthscsa.edu)  
Mobile (1-507-250-2508)



### ABOUT MY WORK TO SUPPORT PATIENTS:

Dr. Ruben Mesa is the Executive Director at the Mays Cancer Center, at UT Health San Antonio MD Anderson Cancer Center. The Mays Cancer Center is one of only four National Cancer Institute-designated Cancer Centers in Texas. For almost 30 years the cancer center has had a deep focus on providing world class cancer care, advancing cancer research and educating the next generation of cancer care scientists and care providers. After earning degrees in nuclear engineering and physiology, with minors in radiation biophysics and bioengineering, from the University of Illinois at Urbana-Champaign, Dr. Mesa received his medical degree from the Mayo Graduate School at the Mayo Clinic College of Medicine in Rochester, Minnesota. He completed his residency in internal medicine and his fellowship in hematology/medical oncology at Mayo. He is a fellow of the American College of Physicians and is certified by the American Board of Internal Medicine in internal medicine and medical oncology. Dr. Mesa was the Chair of Hematology and Medical Oncology for the Mayo Clinic in Arizona and Deputy Director of the Mayo Clinic Comprehensive Cancer Center until transitioning to San Antonio. Dr. Mesa's own practice builds on his role as an international expert on myeloproliferative neoplasms (MPNs), a group of bone marrow disorders that often lead to leukemia. He has been involved in MPN research for more than 20 years. He led the development of National Comprehensive Cancer Network's panel guidelines, the first U.S. guidelines on the diagnosis and treatment of myelofibrosis, polycythemia vera and essential thrombocythemia. Dr. Mesa has been the principal investigator or co-principal investigator of more than 100 clinical trials and has authored over 400 peer reviewed manuscripts. He was a co-leader contributing to the FDA's approval of ruxolitinib for polycythemia vera and myelofibrosis, and fedratinib for myelofibrosis. He is currently leading the investigation of several other drugs for these types of cancers. Dr. Mesa was elected to the Board of Directors, and subsequently to the executive committee, of the Leukemia and Lymphoma Society, and sits on the board of the MPN Education Foundation. Dr. Mesa is the editor in chief of Current Hematologic Malignancy Reports has been an active member with AACR, ASH and ASCO with a variety of leadership roles.



**Prof. Tiziano Barbui**  
Foundation of Clinical Research-FROM  
**Italy**

*How to contact me:*

[tbarbui@fondazionefrom.it](mailto:tbarbui@fondazionefrom.it)

**ABOUT MY WORK TO SUPPORT PATIENTS:**

Tiziano Barbui is professor of Hematology and founder of the Department of Hematology at Bergamo Hospital. He is currently the Scientific Director of Clinical Research Foundation (FROM) at Papa Giovanni XXIII Hospital, Bergamo (Italy).

Professor Tiziano Barbui published more than 700 scientific articles in International peer reviewed journals. During the European Hematology Association (EHA) meeting in Stockholm (2013), he received the Jean Bernard award for his contribution to optimization of diagnosis, prognosis and therapy of the Myeloproliferative neoplasms and for establishing international networks for clinical research in Hematology. He currently chairs the European Leukemia Net group on Myeloproliferative Neoplasms.

## Werner Zinkand

MPN-NETZWERK E. V.  
Germany

### How to contact me:

w.zinkand@mpn-netzwerk.de  
++49 157 78 97 33 20



### MY STORY:

In summer 2011 I got the diagnosis Polyzythemia Vera. In autumn we started in Munich, where I live, a regional group, which is meeting 8 or 9 times a year. In the beginning of 2012 I became a member of the german mpn-netzwerk. In the same year I was elected as one of the 5 board members of this network.

Till now I can live very well with PV and I hope, the research on mpn will go on and find some helpful therapies. For me it is very important to share our knowledge and experience about our disease with others.

### ABOUT MY ORGANISATION:

The German mpn-netzwerk e. V. is a non-profit support organisation for patients diagnosed with myeloproliferative neoplasms and also for their family members. Run entirely by patient volunteers, our mission is to support each other and exchange experience and health information, which help manage the physical, emotional and social effects of living with a myeloproliferative neoplasm.

Our network is running a homepage: [www.mpn-netzwerk.de](http://www.mpn-netzwerk.de), where you can find a lot of informations about mpn. At the moment we have about 660 members, who can share their experiences in our internet forum. We also offer 3 brochures on ET, PV and PMF, which you can download from our website or order for free at [broschueren@mpn-netzwerk.de](mailto:broschueren@mpn-netzwerk.de).

We have regional groups and once a year we are organizing a big open meeting for patients and their families with lectures of specialists for all mpn diseases.

There is a law in Germany, that the health insurance companies have to spend money for self help groups, so we are glad to be independent from pharmaceutical industries.



## Wonyoung Jang

**KBDCA (Korea Blood Disease & Cancer Association)  
South Korea**

*How to contact me:*

E-mail: [bloodcancer@daum.net](mailto:bloodcancer@daum.net)  
phone: +8210-6402-6553  
Instagram User ID: kbdca

### MY STORY:

I'm a General manager of Korea Blood Disease & Cancer Association.

In my role as manager of KBDCA, I mainly work planning and managing business and leading support groups.

My wish is to make more patients more sensitive care for MPN patients.

### ABOUT MY ORGANISATION:

Korea Blood Disease & Cancer Association(since 1995) is a nonprofit organization that helps Blood disease and cancer patients to rehabilitate quickly and to go back to their normal life.

KBDCA is contributing to the promotion of health and welfare by carrying out various projects such as financial support, education & counseling programs, information support, and overseas exchange.

We help patients with blood diseases and cancer to be cured promptly and to complete their rehabilitation successfully.

# WHO'S HERE FROM OUR SPONSORS

Sponsors

**PharmaEssentia**

 **SIERRA**  
ONCOLOGY

 **Roche**

 **AOP ORPHAN**  
FOCUS ON RARE DISEASES



## **Donna Merrigan**

Sierra Oncology

VP, Global Medical Affairs

## **Jucinda Fenn-Hodson**

Roche Genentech

Global Patient Partnership Director

## **Michael Korbonits**

AOP Orphan

Medical Manager

## **Olaf Brandenburg**

AOP Orphan

Key Account Manager

## **Olena Weissenbacher**

AOP Orphan

Corporate Communication

## **Peter-Christian Reinhart**

AOP Orphan

Key account manager

## **Rachael Foggo**

Sierra Oncology

Senior Director, Global Marketing

## **Fabian Kruse**

AOP Orphan

Marketing Manager

## **Craig Zimmerman**

Pharmaessentia

VP Medical and Development

## **Roland Bindeus**

AOP Orphan

# Sponsorship Acknowledgement

We would like to thank the following sponsors for providing unconditional educational funding. Without their support, this conference would not be possible:

## *Sponsors*



**AOP ORPHAN**  
FOCUS ON RARE DISEASES



# MPN HORIZONS

**2020** LEARN, SHARE, GROW

MINI VIRTUAL CONFERENCE

5<sup>th</sup> INTERNATIONAL CONFERENCE  
FOR ORGANIZATIONS REPRESENTING  
PEOPLE WITH MPN



**MPN** Advocates Network

