

REPORT

CML HORIZONS 2013, Prague 3-5 May 2013

11th INTERNATIONAL CONFERENCE FOR ORGANIZATIONS REPRESENTING PEOPLE WITH CML



CML HORIZONS 2013 IN PRAGUE: LEARN, SHARE, GROW

Over the past 11 years, the CML Horizons conference has become the main global conference for CML patient organizations. The 11th CML Horizons Conference was held in Prague, Czech Republic, from May 3-5, 2013 and hosted by the non-profit Leukemia Patient Advocates Foundation. “We were thrilled to have 141 participants from almost 60 countries in Prague”, said **Jana Pelouchová** on behalf of the CML Advocates Network. “The conference once again demonstrated the great power of the global community: inspiring best practice presentations, posters, marketplace and action forum sessions as well as fantastic updates by CML experts”, she said. Besides providing scientific knowledge and advocacy skills, CML Horizons 2013 demonstrated that over the years the community has developed a unique collaborative spirit across borders and regions.

The conference theme, helping patient advocacy leaders to “learn, share and grow” their knowledge, was in full evidence during the three days of sessions focused on CML

treatment and advocacy for patients. Medical sessions covered current best practice and latest developments in CML therapies, monitoring and management, as well as reflections on where research is headed in the future. Advocacy sessions examined access barriers; shared best practices from several patient organizations, and also took on specific topics for the CML Advocates Network as an organization. The gathering also provided an invaluable way for participants to network with each other and form relationships that will extend their effectiveness as patient advocates.

11TH CML HORIZONS 2013 - DAY 1

WELCOME TO PRAGUE

Jana Pelouchová, chair of the Diagnoza CML support group and a co-founder of the CML Advocates Network, provided a warm welcome on behalf of the host country, the Czech Republic, and the city of Prague. Additional greetings came via video from internationally known Spanish tenor José Carreras, founder of the José Carreras International Leukaemia Foundation, established following his own recovery from the disease in 1988.

CML ADVOCATES NETWORK UPDATE

Giora Sharf, founder of the Israeli CML Patients Organization and co-founder of the CML Advocates Network, provided an update on the work of the CML Advocates Network and the Leukemia Patient Advocates Foundation. He noted that the CML Horizons conference has grown from 28 patient leaders meeting in 2002 to the 2013 event with more than 140 people in attendance from nearly 60 countries. Founded in 2007 by four advocates, the CML Advocates Network has grown to a vivid network that, at the time of the conference, included 73 leukemia patient organizations in 57 countries on all continents. Key drivers include a public directory of CML groups and using the virtual platform and social media to enhance communication among CML advocates to build skills, coordinate campaigns, build partnerships and share knowledge.

Network achievements were also noted, including supporting campaigns for treatment access, holding presentations at major conferences like EHA, ISH, ELN and ASH; global participation in World CML Day; development of patient-friendly summaries of ELN Treatment Recommendations for CML in 10 languages; completing two phases of an Adherence Survey with almost 2600 responses from 79 countries; conducting the CAM Survey (on the use of complementary and alternative medicine in CML); the CML Generics Survey (55 countries responded); the EHA Patient Advocacy Session; development of "Informal Partnerships" with organizations such as EHA, GIMEMA, French and German Study Groups, EBMT Nurses, "Rare Cancers Europe" and PatientPower, plus continued progress in pediatric CML through the Junior CML Advocates.

Giora stressed that participation of members make the group successful. The Network, he said, "will only be successful if members engage, contribute and drive initiatives. Together we can make the difference!"

EUROPEAN PRE-MEETING

Chairs: Jana Pelouchová & Tony Gavin

- **Health Technology Assessment and patient involvement from a European perspective** (Martin Visnansky, Foundation SRAK-SLOVAHTA, Slovakia)
- **Health Technology Assessment and CML: involvement in practice** (David Ryner, The CML Support Group, UK)
- **Cross border healthcare in the EU** (Šarūnas Narbutas, ECPC / POLA, Lithuania)

While the official program of the global CML Horizons meeting started on Friday afternoon, the morning was used by the European delegates to discuss issues of specific interest in European health policy, such as European cross-border healthcare and patients' rights, as well as Health Technology Assessment.

The first part of the European pre-meeting session was dedicated to Health Technology Assessment (HTA) and value assessment methodologies deployed in Europe, presented by **Martin Visnansky**. A widely-used definition of Health Technology Assessment developed by HTAi and INAHTA and published in *International Journal of Technology Assessment in Healthcare*, is that "HTA is the systematic evaluation of the properties, effects and/or other impacts of health care technology". Its primary purpose is to provide objective information to support health care decisions and policy making at the local, regional, national and international levels. Jana Pelouchová emphasized that Health HTA is a term that patient advocates need to become familiar with, as new CML treatments are entering the market which might be subject to HTA assessment. The sessions helped to understand the concept of HTA and learn how to use the term in our daily advocacy work.

David Ryner presented a very practical approach to HTA, whereby he focused on his involvement in appraisals of UK's HTA body National Institute for Health and Care Excellence (NICE). David described HTA in the UK as a highly rule-bound system. This is why

it is very important for patient advocates to understand the rules, to understand the gaps between theory and reality in patient involvement in the process, and how to utilize those gaps for advocacy. David encouraged patient advocates to engage in HTA, and emphasized that *“small gains are better than no gains”*. Getting involved is the only way to help decision makers understand the impact of disease and therapies, to raise awareness of real patients' needs, to make shared decision making on which drugs and treatments are made available a reality, and to finally give CML a priority in healthcare systems across Europe.

Šarūnas Narbutas' presentation on “cross border healthcare” came in a very timely manner, as a new EU legislation is framing the right of EU citizens to access health services in other EU Member States. Sarunas highlighted the new rules regarding prior authorization of cross-border health services, mutual recognition of prescriptions for drugs, and reimbursement of costs. All this is relevant for CML patients that may need to access CML treatment or clinical trials in another EU Member State. The European directive is currently being transposed into national law in all EU Member States.

IDEAL WORLD VERSUS REALITY: NEW CHALLENGES WITH SUBSTANDARD DRUGS & GENERICS

Chairs: Viji Venkatesh & Jan Geissler

- **Generics, Biosimilars, Copies, Substandard Drugs: Efficacy, Efficiency, Sustainable Quality? What is the Difference?** (Dr. Sabine Kopp, WHO Medicines Quality Assurance Programme, Switzerland)
- **Originals, Generics, Copies: Results of the CML Advocates Network Survey** (Jan Geissler, CML Advocates Network, Germany)
- **Actions of CML groups: Fighting against Anzovip, a generic drug** (Jelena Cugurovic, CML Association of Serbia)

Friday's first session dived into the challenges patients now face in a world of original drugs, generic drugs, copy drugs and more. **Dr. Sabine Kopp** from the World Health Organization explained the differences between generic, biosimilar and “copy” drugs, with a focus on understanding underlying principles and potential differences in quality, efficacy and safety. She said falsified medicines, both of generic and branded products, is a growing, increasingly sophisticated business. Government's role in regulating drug distribution was discussed. The lack of government commitment to create a strong medicines regulation was identified as one important factor that encourages bad quality medicines, and she highlighted the importance that patient advocates support their governments in establishing and maintaining of an efficient medicines regulatory system. Patient organizations should “promote the importance of implementation of current good practices and international standards from development to distribution to ensure quality, safety and efficacy of medicines”. She also called on attendees to encourage patients to make purchases from reliable sources such as licensed pharmacies, and to report “suspect medicines”, and collaborate internationally on serious events. Additional cautions for patients included making sure packages are sealed, checking package information for proper information including the drug name, manufacturer, expiration date and use instructions; not purchasing unpackaged medication; and reporting suspicious medications to a pharmacy, healthcare provider or regulatory agency.

Jan Geissler shared results of the recent CML Advocates Network Survey on original, generic and copy drugs which gathered 86 responses collected from 55 countries within four weeks. While original, patented drugs are available in all 55 countries, generic and copy drugs, first introduced in India eight years ago, are increasing in number and were reported to be in use by 14 countries. Jan cited steps organizations are taking to face the spreading

of low-quality, substandard drugs. Patient groups were requested to take a close look at new drugs entering the market in order to ensure the safety of their members.

A specific example of fighting against a questionable generic drug was given by **Jelena Cugurovic**, of the CML Association of Serbia, one of the first countries in Europe in which a generic CML drug was introduced. The State Health Insurance Fund approved imatinib named Anzovip manufactured by Actavis to be used instead of Glivec. All patients on Glivec were switched to generic drug Anzovip, even though there was little information about the drug itself and its usage. It was assumed that the drug was produced in India and only repacked in Serbia. After getting no answers to formal queries of government officials, the patient group took their case to the media. CML Serbia got great support by the most important media and finally started getting some answers to their questions. Together with the hematologists treating CML patients the group very carefully monitors patients to determine if the generic drug is having a negative impact on response and the toxicity. Thanks to the CML Association of Serbia, today an increased number of patients can get a branded second generation CML drug as their treatment medication when required. Branded second generation drugs have also been made available as first line therapy. Advices for attendees included having realistic goals, acting early if rumors circulate about generic drugs so as to not lose valuable time, and to focus on ensuring that only high quality generics produced by reliable companies are introduced in their respective country.

CML #1: CML UPDATE

Chairs: Anita Welborn & Zhenxi Zhong

- **All available drugs from clinical/efficacy point of view - how do they compare?** (Dr. Gianantonio Rosti, St Orsola University Hospital Bologna, Italy)
- **All available drugs from a side effect point of view - how do they compare?** (Dr. Dina Ben Yehuda, Hadassah Medical Center Jerusalem, Israel)
- **Most potent induction, or early escalation on the most affordable drug? Context of therapy optimization and costs** (Dr. Tim Hughes, Department of Haematology at IMVS, Australia)

With seven first, second and third generation CML drugs in existence now, **Dr. Gianantonio Rosti** from Italy discussed the efficacy, or effectiveness, of the older drugs versus newer ones. Most of his talk compared clinical trial results of imatinib against nilotinib, with the second generation nilotinib showing earlier and more marked reduction of disease. He said patients with a marked decrease of disease early on (after three months) show a higher probability of reaching complete molecular response.

While tyrosine kinase inhibitors have greatly improved survival rates for CML patients, and are well tolerated by most patients, they are not entirely BCR-ABL specific, leading to off-target side effects. **Dr. Dina Ben Yehuda** said understanding side effects is important for determining the right treatment course and tests or interventions needed to prevent additional health complications. Adverse hematologic impacts reported from imatinib, nilotinib and dasatinib include neutropenia (low white cells), thrombocytopenia (low platelets) and anemia. Other side effects reported from these TKIs include diarrhea, fatigue, headache, nausea, vomiting, peripheral edema, superficial edema, pruritus, rash, and pleural effusion. She noted that nilotinib and imatinib resulted in more reports of edema and skin problems while more pleural effusion was reported with dasatinib.

Dr. Ben Yehuda also provided an in-depth look at the facts and myths about long term adverse effects. Summarizing, she said cardiac (heart) problems are rare and mostly seen in patients with previous or underlying cardiac issues. In terms of possible immune system impact and development of another cancer, she cited a 10-year plus study at MD Anderson showing 3,000 CML patients on TKIs have the same level of infectious diseases and of secondary cancer development as the general population. Acute renal failure has been reported in some patients, but little data is available to date. A small percentage of patients are reporting memory loss and erectile dysfunction as side effects. In terms of fertility, she advised that it is now considered safe for men on imatinib to father children but that less is known about newer TKIs and men should take precautions. Women continue to be advised to work with their physicians regarding fertility and pregnancy concerns. Studies for the newest TKI, ponatinib, found side effects included low platelets, neutropenia and anemia, as well as rash, dry skin, abdominal pain, headache, constipation, hypertension, increased lipase levels and pancreatitis. For bosutinib, the BELA Trial found that gastrointestinal and liver-related events were more frequent side effects.

In summary, she said multiple clinical factors need to be taken into consideration in choosing the right TKI, including what she called the “X” factor, or the options the patient may or may not have due to the price and drug availability. She added that physicians generally feel more secure with the first TKI, imatinib, because there is more data available.

Therapy optimization while taking cost factors into consideration, also known as a “sequential approach” to treatment, was addressed by **Dr. Tim Hughes** from Australia. This approach calls for most patients to receive the better known, lower cost imatinib while higher risk patients are switched early to more potent drugs. He also addressed the

question of whether use of a less potent drug will impact patients interested in the potential for treatment free status in the future. He said more evidence and information is needed to determine this, and that if the more potent drugs do provide stronger support for treatment cessation then there is a strong case for placing patients on them. On the other hand, he cautioned, if this is not supported through clinical evidence, then there is little justification for the use of more potent TKIs as frontline therapy except perhaps in selected high risk subsets of patients.

The first day of the conference continued with attendee introductions, reunions and networking in a comfortable and relaxed atmosphere during a nice dinner at the conference hotel.

11TH CML HORIZONS 2013 - DAY 2

CML patient advocate **Zhengchen Liu**, from New Sunshine Charity Foundation in China, got Saturday morning off to a great start by leading the group in Tai Chi, an ancient Chinese tradition that today is a graceful form of exercise. It involves a series of movements performed in a slow, focused manner, with deep breathing. Tai Chi is used for stress reduction and various health conditions, including many cancer survivorship programs today. The session refreshed attendees and helped them focus on the CML sessions ahead of them.

CML #2: PATH TO CURE AND TREATMENT-FREE SURVIVAL

Chairs: Greg Stephens & Niko Lamberts

- **Does transplant still have a role? News in transplant? How to treat advanced disease? Transplant+TKI combination?** (Dr. Jane Apperley, Imperial College London, UK)

- **Latest experience from STOP Trials** (Dr. Tim Hughes, Department of Haematology at IMVS, Australia)
- **What is the "real" cure? Is stopping really a feasible approach?** (Dr. Dina Ben Yehuda, Hadassah Medical Center Jerusalem, Israel)

Dr. Jane Apperley provided an overview of the historic and current role transplant plays in CML treatment through a series of case studies, showing that while the percentage of patients having transplants has markedly decreased it is still the only course of treatment for some patients with advanced disease. Her key point was that while transplants are rare today they must remain an option for the CML patients who need them and to identify those who would benefit much earlier in the process instead of after patients have failed multiple TKIs, which makes the transplant process more complex.

Dr. Tim Hughes focused on data from clinical trials exploring treatment free remission or treatment-free remission, also known as STOP trials. He shared arguments being made in the medical community both for and against TFR as a goal for patients, and stated that there is not enough data at this time to reach a clear answer. He said further studies are needed, and two international trials started recruiting patients in early 2013. The global medical community is moving toward a new medical management model for CML in which the goal would be to manage the initial aspects of treatment during the first years of treatment so the patient is best positioned to achieve a sustained CMR (Complete Molecular Response) and go off therapy.

Dina Dr. Ben Yehuda shared the differing view on a "real cure" for CML. While some view stopping the progression of disease, or an "operational cure" as acceptable, others define a true cure as including the elimination of leukemic stem cells. She stated that "operational cure" is being achieved now for most patients, but additional research is needed to make it clearer which patients can safely stop therapy and to determine how to eliminate leukemic stem cells.

EXPERTS MARKET PLACE

The Expert Marketplace is a series of interactive session with very short, speaker presentations followed by concise, focused discussions. The purpose is to provide participants with the opportunity to discuss topics with experts in an informal small group setting. Participants could choose three out of the following four topics offered:

- **Using the Internet for CML advocacy** (Kris Griffin, "Access CML Drugs" Blog, UK)
- **How to Advocate to Policy Makers** (Nicola Bedlington, European Patients' Forum)
- **Working with Pharma** (Sandy Craine, CML Support UK; Helen Roberts, Novartis Oncology)
- **How to Run a Patient Group Meeting** (Viji Venkatesh, The MAX Foundation, India; Markus Wartenberg, Das Lebenshaus e.V., Germany)

In these sessions, which were repeated so attendees could attend multiple presentations, practical advice was given to help advocates when they returned to their home countries. Blogger **Kris Griffin** showed how he uses the Internet and Social Media for CML advocacy, and also blogged each day of the conference. **Nicola Bedlington** explained how to advocate to policy makers and gave practical examples on how to bring forward political messages proactively and reactively, when to provide scientific or anecdotal evidence, and when to advocate for their own disease and when better to address the broader picture through alliances like the European Patients' Forum. **Sandy Craine** and **Helen Roberts** shared examples of how a UK CML patient group works within government regulations and other requirements to obtain financial support from pharmaceutical firms while also maintaining the independence of the patient group. **Viji Venkatesh** and **Markus Wartenberg** gave pointers on how to organize and conduct face-to-face support meetings for CML patients.

CML #3: CML IN REAL LIFE - QUALITY OF LIFE, ADHERENCE AND PREGNANCY

Chairs: Sandy Craine & Jan De Jong

- **CML and Quality of Life: What is the impact of life-long CML therapy on Quality of Life?** (Fabio Efficace, GIMENA, Italy)
- **Results from our Global CML Advocates Adherence Survey** (Giora Sharf, CML Advocates Network, Israel)
- **CML and pregnancy, how to plan a family** (Dr. Jane Apperley, Imperial College London, UK)

Fabio Efficace started off the session, stating that there is little evidence now on the quality of life (QOL) impact that targeted therapy has on the physical and mental health of patients, that this area requires urgent attention, and will be the next key focus of CML research. He stated that physicians tend to underestimate the burden of symptoms experienced by patients. He also shows a recent study, published in *Leukemia* (conducted by his research group), demonstrating that, out of all symptoms reported by patients receiving long-term imatinib therapy, fatigue is the crucial one greatly impairing patients' life.

QOL concerns were further addressed by **Giora Sharf** as he reported results on the Global CML Advocates Adherence Survey. Those with low adherence perceive their QOL to be affected, worry about the long term effects of treatment and have less understanding of the consequences of skipped doses. Those with higher adherence were more satisfied with the information they received and also perceived their medical team members to be approachable. Recommendations coming from the study include the use of reminder tools, stronger patient education, focused attention on patients most at risk and working with physicians to help them play a stronger, supportive role in counseling patients about adherence.

Fertility and pregnancy were discussed by **Jane Apperley**, who emphasized that fertility

should be taken into consideration at the time of diagnosis for those who wish to conceive. She reported on a study of 60 pregnancies in partners of men on imatinib that found no suggestion of any problems in conception, pregnancy, and delivery or of any increase in congenital abnormalities. For female CML patients, the situation is different, with outcomes for women on imatinib during pregnancy including fetal abnormalities and spontaneous abortions, as well as normal live infants. Advice for women will vary depending on the state of disease and disease response. Generally the deeper the female patient's level of response prior to stopping treatment for pregnancy, the more likely she is to get it back when she resumes treatment. There is little hard data at this time on the impact of second and third generation TKIs on pregnancy and her advice was for the female patient to stop treatment or postpone its initiation.

BEST PRACTICES IN CML ADVOCACY

- **Rising Sun, a Network of CML advocates from the Asia-Pacific region** (Rod Padua, Touched by Max, Philippines)
- **Counseling sessions with haematologists as volunteers for patients** (Milena Remic, Slovenian Lymphoma and Leukemia Patient Association)
- **Advocacy networking - Joining forces with like-minded organizations to spread cancer awareness** (Ferdinand Mwangura, Henzo Kenya)
- **CML Life Africa** (Bahija Gouimi, Amal, Morocco)
- **What is My PCR? A global awareness campaign** (Pat Garcia-Gonzalez, The MAX Foundation, USA)
- **Quality of Life Survey** (Cheryl-Anne Simoneau, The CML Society, Canada)

The sharing of best practices was very popular at the conference. **Rod Padua** showed how Rising Sun has grown into a community-driven group uniting 18 organizations from 25 countries from the Asia-Pacific region to focus on CML patient support. **Milena Remic** detailed a "hematologist counseling" program

offered to patients in which they are invited to informal meetings with a hematologist who volunteers to counsel patients by providing detailed educational information about the disease and living with CML. **Ferdinand Mwangura** gave an example of increasing visibility and effectiveness by partnering with other cancer organizations, which his group did for a cycling race. **Bahija Gouimi** spoke about the formation of “CML Life Africa” which brought patient advocacy leaders from 12 African countries together for the first time in 2012, has established ongoing communications between the groups, is now reaching out to others and will hold a collaborative workshop in late 2013. **Pat Garcia-Gonzalez** provided details on the “What is My PCR?” initiative, a patient-driven global awareness campaign to increase awareness of the need to regularly monitor CML treatment results with a goal of optimizing clinical outcomes. More than 32,000 campaign buttons have been distributed and 36 organizations are now partnering in the campaign. A special moment came when Pat pointed out that one of the conference attendees, Kitti, was the inspiration for the campaign and he stood up to the group’s applause and recognition. **Cheryl-Anne Simoneau** shared results of a multi-country patient survey on quality of life. The QOL II study takes a deeper look at key QOL indicators that were highlighted from the 2008 study, which was presented at a satellite symposium at the American Society of Hematology (ASH) conference. Respondents reported marked declines in their quality of life since starting treatment, including 40% of patients reported that household income was lower. The study also disclosed serious issues regarding patient knowledge of treatment milestones or the need for adherence. A key finding was that the better the side effect management, the better the rate of adherence, response and quality of life. An Abstract for the study has been submitted to several organizations for full presentations at medical conferences in the near future.

CML STEERING COMMITTEE ELECTIONS

The CML Horizons conference is governed by a global steering committee consisting of CML patient advocates from North America, Latin America, Asia, Europe, Middle East and Africa.

Those elected or re-elected to serve a two year term at the 2013 meeting were:

- Anita Welborn (USA, for North America)
- Bahija Gouimi (Morocco, for Africa)
- Mina Daban (France, for Europe)
- Pat Garcia-Gonzalez (USA, for Latin America)
- Zhengchen Liu (China, for Asia-Pacific)

Additional Steering Committee members are:

- Giora Sharf (Israel/Middle East)
- Jan Geissler (Germany/Europe)
- Jana Pelouchová (Czech Republic/Europe)

The audience gave great applause to the Steering Committee’s work over the past two years, and special thanks were expressed to Euzebiusz Jan Dziwinski from Poland whose term on the Steering Committee ended at the meeting.

A RELAXING EVENING AT THE HEART OF PRAGUE

After a full day of learning, attendees were ready to relax and gathered outside the hotel for dinner. To their delight, transportation was via the city tram winding along cobblestone streets and past magnificent buildings, glamorous shops, residential areas, beautiful monuments and more, giving a good view of the beautiful city of Prague. With 1.3 million residents, the historic city is at the center of the Czech Republic in Central Europe.

Dinner took place at the Kaiserstein Palace, originally built in 1654 and now a historical landmark. The group was treated to a special reading of the children’s book, ***Máximo and the Big C***, by author Viji Venkatesh (The MAX Foundation, India), with the support of María Isabel Gómez (ASAPHE, Venezuela) and The MAX Foundation, USA. The book tells the

story of how Máximo, a little sparrow, is able to overcome his fear of flying in order to help others. The moral of the story is that we all have the strength inside of ourselves to overcome the fear of a cancer diagnosis; and that it is by giving ourselves to others that we defeat the Big C. The evening also included great food, conversations and networking.

11TH CML HORIZONS 2013 - DAY 3

CML #4: MONITORING & GUIDELINES

Chairs: Pat Garcia-Gonzalez, Giora Sharf

- **The basic monitoring before we can talk about "cure"** (Katerina Machova-Polakova, Institute of Hematology and Blood Transfusion Praha, Czech Republic)
- **New and Advanced Monitoring Techniques – and Their Costs** (Dr. Tim Hughes, Department of Haematology at IMVS, Australia)
- **What Do the Treatment Guidelines Say? Update on the New ELN, NCCN Recommendations** (Dr. Gianantonio Rosti, St Orsola University Hospital Bologna, Italy)

Katerina MachovaPolakova provided an overview of cytogenetic and molecular monitoring of CML patients, as well as the basics of mutations testing and monitoring. She said cytogenetic testing is of most value in the diagnostic process and until complete cytogenetic response achievement during the treatment while molecular monitoring is critical for measuring deeper responses and early detection of development of resistance and/or disease progression.

Tim Hughes discussed the future of CML molecular testing, and shared information on the Cepheid GeneXpert instrument as next generation BCR-ABL testing. This system is automated, highly accurate, and can produce reports in two hours. The unit controls for variations between samples and also standardizes results reporting to the International Scale. Sensitivity is comparable to current testing, but a new version is in development that is expected to be able to

increase the sensitivity of BCR-ABL1 detection by 1 log to 4.5.

Gianantonio Rosti provided an update on new ELN (European Leukemia Net) and NCCN (US) guidelines for physicians in the treatment of CML. ELN expert recommendations had just been accepted for publication on the journal *Blood*. He highlighted that clinical data generated during the last 5 years have confirmed that achieving earlier responses (at 3 and 6 months after starting the treatment) is associated with a significantly reduced probability of a progression of the disease and a significantly better long-term outcome. The importance of early responses has now been reflected in the new ELN Recommendations.

ADVOCACY IN ACTION: THE ACTION FORUM

Chair: Kathy Redmond

These sessions, known as the CML Advocacy Marketplace, provide participants a "marketplace island setting" with the opportunity to learn about, and get involved in, key advocacy initiatives that impact the global CML patient community.

- **How to Increase Engagement on World CML Day** (Kathy Redmond, Educational Consultant, Switzerland & Erin Schwartz, The MAX Foundation, USA)
- **Increasing Capacity in CML Groups, Introducing Training** (René Steuer, Brazilian Association of Fundraising Executives)
- **Call for Better Care: Updating the Baveno Declaration** (Pat Garcia-Gonzalez, The MAX Foundation, USA)

While attendees went to the breakout session of choice, they learned the results of all three sessions in the follow up report which followed. **Erin Schwartz** reported that the group focused on World CML Day agreed on the need for collaboration among advocacy groups, including sharing a mutual theme for the day for global "awareness" while implementing "action" at the local level. A working group is being formed to fine tune

the specifics of moving forward for 2013's campaign.

Pat Garcia-Gonzalez reported on the Baveno Declaration which was developed in 2008 and is similar to what is known as a patient bill of rights in many countries. The workshop attendees noted that it is not clear who the audience is for the declaration, actionable points are needed, measurements are needed and it should be shorter. The group decided to form a team to update and refine the declaration to be specific, achievable and measurable.

René Steuer said his group focused on how groups were run in Latin America, saying that early on they were run from the heart, and a key need was to bring professionalism and organization to the groups to make them more effective. He concluded advocacy groups need proper development of their mission and objectives to be successful, including an understanding of what is being done that should not be done, and what is not being accomplished that should be done. He also said it was important to prioritize and do a few priorities well instead of having too many and not being able to meet them.

BEST POSTER AWARD AND MEETING CLOSE

The conference closed with the acceptance of the "Best Poster Award" by Mina Daban on behalf of LMC France, for her group's poster of events that created greater awareness of CML and gave hope and encouragement to CML patients and their families. Many great posters were submitted and were on display for all to enjoy throughout the conference.

In summary, the CML Horizons 2013 conference demonstrated the growth of the global community of patient advocates working on behalf of those impacted by CML through sharing information and best practices from all corners of the globe. The event will no doubt lead to a great CML Horizons 2014! Special thanks to the speakers for sharing their knowledge, the CML Steering Committee for putting together an informative program, and to every advocate who works on behalf of the CML community!

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For Additional Information

- Video and PDF Presentations:
<http://www.cmladvocates.net/cmlhorizons2013>
- Photo Gallery:
<http://www.cmladvocates.net/photo-gallery/cml-horizons-2013>
- CML Advocates Network website:
<http://www.cmladvocates.net/>

About CML Horizons 2013 and this report

The CML Horizons 2013 conference was hosted by the non-profit Leukemia Patient Advocates Foundation, and was governed and organized by a global steering committee of CML patient advocates from North America, Latin America, Asia, Europe, Middle East and Africa. The CML Steering Committee 2011-2013 was:

- Anita Welborn (USA/North America)
- Bahija Gouimi (Morocco/Africa)
- Eusebius Jan Dziwinski (Poland/Europe)
- Giora Sharf (Israel/Middle East)
- Jan Geissler (Germany/Europe)
- Jana Pelouchová (Czech Republic/Europe)
- Pat Garcia-Gonzalez (Latin America)
- Zhengchen Liu (China/Asia-Pacific)

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Pat Elliott (National CML Society/USA) and Jan Geissler (Co-founder CML Advocates Network)

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