Executive Summary

The 2015 Rising Sun Meeting for patient advocates took place from October 9th through 11th in Bangkok, Thailand. The meeting was a multi-sponsored initiative made possible thanks to Novartis Oncology’s support as the premier sponsor with additional support from Janssen Asia Pacific, Ariad and Otsuka.

Beginning in 2015, the Rising Sun Meeting structure has been renewed and the conference is now officially under the auspices of The Max Foundation, in partnership with leaders of patient organizations from Asia Pacific and South Asia whose mission is to serve people living with chronic myeloid leukemia (CML) in their countries. The Max Foundation also serves as the official Secretariat, coordinating the meeting activities in liaison with the Steering Committee Members.

The Rising Sun Meeting is an opportunity for the network members in the region to come together for disease related medical updates, best practice sharing and capacity building. The goal of the annual gathering is a desire to convene a meeting with relevance to stakeholders within the region specifically, and as a result, the meeting content and agenda is driven by the needs of the regional constituents. A total of 23 organizations participated in this year’s Rising Sun, represented by 37 patient advocates and seven speakers.

The Rising Sun Meeting aims to address the following:
- Medical education, including disease related updates and discussions
- Advocacy and capacity building
- Best practice sharing

Two highlights of this year’s Rising Sun Meeting were, going beyond CML, and chronic lymphocytic leukemia (CLL) was included in the agenda for the first time. Secondly, patient groups from Mongolia and Uzbekistan were invited to this year’s meeting, making it a comprehensive regional meeting.

Presentations by regional Key Opinion Leader physicians served as the mainstay of the Medical Sessions, ensuring that the updates were topical for the audience and based on best practices from across Asia. Fundraising was chosen as the focus of advocacy and capacity building. The Fundraising Session contained a presentation by an expert in the field as well as an interactive group workshop. Best practice sharing took the form of oral presentations and poster presentations by participating advocates from different countries.

Participation in the Rising Sun Meeting is a unique opportunity that brings together patient leaders and leading physician representatives of the Asia Pacific community. The organizations that participated in the meeting remain committed to increase access to treatment, education and awareness within the respective region. It is the aim of The Max Foundation as well as the Steering Committee that Rising Sun would develop to be a leader in providing training in capacity building, and acts as the platform for groups to share their best practices to enable they learn from each other. The ultimate goal is to empower patient leaders to involve themselves in advocacy work within their local communities.
Background

Rising Sun brings together chronic myeloid leukemia (CML) focused patient groups and organizations across the Asia Pacific region with one common goal: that of enhancing access to treatment and bringing awareness to the CML patient community in the region. The Rising Sun Meeting was first conducted in April 2010 at Hong Kong with only 10 participating countries from the Asia Pacific Region. Since then, the subsequent meetings have successfully gathered more than double that number of CML groups and leaders in the following cities across the Asia Pacific region:

2015: Bangkok, Thailand
2014: Penang, Malaysia
2013: Beijing, China
2012: Kuala Lumpur, Malaysia
2011: Singapore

Starting from 2015, Rising Sun has officially been organized under the auspices of The Max Foundation, in partnership with the patient advocacy groups in the Asia Pacific Region, in driving and coordinating its activities. It has also grown beyond Asia Pacific Region to include patient advocate groups in South and Central Asia.

From its humble beginnings, the Rising Sun Meeting for advocates has expanded rapidly to include delegates from 19 different countries in the Asia Region all of whom came together in the year 2015.

The 2015 Rising Sun Meeting was held on 9 – 11 October at Courtyard by Marriott, Bangkok, Thailand.

Meeting Objectives

✓ Improve awareness of CML in patient groups for best practices and improved management of CML.
✓ Improve awareness of CLL among participating patient group leaders for better disease understanding.
✓ Provide opportunities for sharing and learning amongst participating support groups and organizations.
✓ Enhance capacity of participating patient groups and organizations through educational activities.
**Participant List**

Participants are patient advocacy group leaders from the Asia Region who are part of the Rising Sun 2015 Meeting. In addition to the delegates, the participant list also includes the invited speakers and industry partners.

<table>
<thead>
<tr>
<th>Name of Organization</th>
<th>Country</th>
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<tbody>
<tr>
<td>Leukaemia Foundation Australia</td>
<td>Australia</td>
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<td>Bangladesh CML Supporting Group</td>
<td>Bangladesh</td>
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<td>Max Miracle</td>
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<td>Shanghai Roots and Shoots</td>
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<td>Friends of Max</td>
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<td>Himpunan Masyarakat Peduli ELGEKA</td>
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<td>Yayasan Kanker Indonesia</td>
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<td>IZUMI</td>
<td>Japan</td>
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<td>Zero Club (CML Patient Group)</td>
<td>Korea</td>
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<td>Korea Blood Cancer Association (KBCA)</td>
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<td>Max Family Society Malaysia</td>
<td>Malaysia</td>
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<td>National Cancer Council of Mongolia</td>
<td>Mongolia</td>
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<td>Blood Cancer Society Nepal</td>
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<td>KIRAN</td>
<td>Pakistan</td>
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<td>Cancer Warriors Foundation</td>
<td>Philippines</td>
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<td>Touched By Max, Inc. (TBM)</td>
<td>Philippines</td>
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<td>Children's Cancer Foundation (CCF)</td>
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<td>Taiwan Bone Marrow Transplantation Association (TBMTA)</td>
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<td>MaxSmiles Thailand</td>
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<td>Thai CML Patient Group</td>
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<td>CML Patients Group Uzbekistan</td>
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<td>Max's VIE</td>
<td>Vietnam</td>
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<td>The Max Foundation</td>
<td>India, Malaysia, Thailand, USA, Uzbekistan</td>
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Meeting Platform

The Rising Sun Meeting had a multi-focused approach, including medical sessions on the latest updates and progress in the treatment of CML and CLL from expert medical speakers, as well as sharing sessions on success stories and challenges presented by patient support and advocacy groups. Fundraising was the topic of primary focus in this year’s capacity building sessions and was conducted via interactive group workshops in the meeting venue.

The sessions held during the three days were conducted either in the format of lectures, interactive workshops, discussions and presentations, showcasing projects and a quiz. In addition to the formal presentations and panel discussions, participants were invited to share their best practices through oral presentations and poster sessions.

The members of the local cancer patient support group in Bangkok offered to host the official Conference Dinner for Rising Sun delegates, during the evening of the second day. The objective was to create an opportunity for a personal and intimate exchange between the participants and the patient group in Bangkok. It was a very special evening for the delegates as they were given a chance to experience the local culture and the warm hospitality. The powerful bonding that formed between the patient group members and the delegates was a testimony to the success of the evening.

The various formats of engagement were aimed to encourage the interaction amongst participants, as well as between participants and speakers with the goal of maximizing the learning experience.

All sessions were conducted in English, with the understanding that all delegates have a basic level of fluency in English.

Agenda

<table>
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<th>9 October</th>
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<th>11 October</th>
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<td>0840 - 0945</td>
<td>0830 – 1030</td>
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<tr>
<td>Pre-Meeting Session</td>
<td>Advocacy 1</td>
<td>Advocacy 5</td>
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<td>Show &amp; Tell, CML Horizons Report, Chai for Cancer</td>
<td>Fundraising Workshop, Wrap Up</td>
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<td>1000 – 1130</td>
<td>1100 – 1230</td>
<td>1100 – 1200</td>
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<td>Opening &amp; CML 201</td>
<td>Advocacy 2</td>
<td>Medical CLL 1</td>
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<td>Fundraising Workshop Part 1</td>
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<td>1130 – 1300</td>
<td>1330 – 1500</td>
<td>1300 – 1545</td>
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<td>Medical CML 1</td>
<td>Advocacy 3</td>
<td>Medical CLL 2 &amp; 3</td>
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<td>Fundraising Workshop Part 2</td>
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<td>1400 – 1600</td>
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<td>Medical CML 2</td>
<td>Advocacy 4</td>
<td>Survey, Closing</td>
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<td>Fundraising Workshop Part 3</td>
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<td>1630 – 1830</td>
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<td>Meeting Ends</td>
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<td>Medical CML 3</td>
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<td>Debrief meeting for relevant parties</td>
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<td>Dinner</td>
<td>Off-site Dinner</td>
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Overviews on the Pre-Meeting Sessions

Patient Group Working Session
This was a follow-up session from last year’s meeting, focusing on facilitating and supporting the young, fledging patient support groups from specific countries in overcoming their challenges. This workshop was facilitated by The Max Foundation representative and the Steering Committee who are experienced patient advocates. Participating patient organizations included groups from Bangladesh, Nepal, Thailand and Vietnam.

CML 201 Session
The goal of this session was preparing the participants for better understanding in the medical sessions. In addition, it also aimed to build engagement among the participants, and also to establish connection with the speakers. This session was conducted in the format of a Quiz Show, where participants were divided into two groups: BCR and ABL groups. It was done differently from the traditional lecture-type session to promote interaction in the room. Each participant had a chance to represent their groups answering CML related questions. Besides the Quiz Master, three expert hematologists played the role of the Judges to further explain each question to make sure participants’ doubts were clear. The format was highly appreciated by all participants, considered as an effective way to learn and familiarize themselves with CML related terms.

Medical Session Summary Points and Key Takeaways

Disclaimer:
This report should not be used in place of medical advice. This is a summary of discussions at one particular meeting. All patients should consult their physicians with any questions.

Chronic Myeloid Leukemia Sessions

CML Session 1
The 2015 Rising Sun Meeting opened with these important topics:

- Updates on treatments, including clinical trials, monitoring and management resistance: International perspectives and current guidelines.
- Monitoring & Resistance: Hong Kong perspective & best practices
- Monitoring & Resistance: Thailand perspective & best practices
Take home messages:

Good response rates are seen with all three main TKIs (Glivec, Tasigna and Sprycel), the best choice of which TKI depends on disease risks as well as toxicity profile. It is always recommended for patients to discuss the options closely with treating physician.

Monitoring the CML patient is an important component in patient care. In the setting of resource limited conditions, physicians are practicing the best possible methods and schedules in making sure the disease status of their patients is well monitored. Compliance and promoting good adherence behaviours remain the most crucial elements in CML treatment. The floor agreed that physician-patient counselling is among the key factors in making sure the patient understands the treatment goals, and the importance of his/her roles in adhering to treatment along the journey.

CML Session 2

CML Session 2A focused on Stop Treatment:

- Stop Treatment: What is being observed internationally and related clinical trials updates.
- Stop Treatment: Data from Asia Pacific Region
- Stop Treatment: Is it possible in Thailand
- Panel discussion: what can the AP advocates community do to help set up the stage for patients having the potential of stopping treatment

Take home messages:

Stopping treatment can only be done in the clinical trial settings at the moment, with stringent monitoring and guidelines implemented. This is what have been currently applied internationally (including Western Countries where we have learned of patients stopping treatment).

In the Asia Region countries, most of the patients do not have access to monitoring tests, especially PCR testing on IS. It is therefore the key priority to ensure PCR IS tests are available to all CML patients.
It is also very crucial for patient advocate leaders to communicate clearly and correctly with fellow patients in their own country on issues related to stopping treatment – patient safety is always the priority and under the current circumstances and situation, all “stop treatment” should be only done under clinical trial setting and under tight supervision of treating physicians.

CML Session 2B focused on Clinical Trials:

- Overview of CML trials in Asia Pacific Region and Advocates’ Roles in CML trials.

Speaker:
Dr Raymond Wong, Hong Kong

Take home messages:
Various CML trials are taking place in the AP region and a good resource reference is: clinicaltrials.gov
Patient advocates’ involvement in clinical trials is important especially from the area of advocates bringing patient perspectives to the planning and implementation of clinical studies.

At the moment in the AP Region, patient advocates’ involvement in clinical trials is not being seen, and it is the hope of the speaker to see partnerships develop between patient advocacy groups and healthcare professionals, as well as the industry working together with them to help cover this aspect.

Among the first steps, a patient advocate group that wants to contribute to CML research must make sure to learn, understand and keep up with medical developments in the field of CML, be clear about country/region healthcare system, establish trust and build relationships with researchers by demonstrating their ability to support research in meaningful way; be a good collaborator and work effectively with all the key stakeholders.

CML Session 3

CML Session 3 focused on Drug Quality and Generics:

- Introduction: How are drugs approved and monitored?
- CML Advocates’ Declaration on Generics
- Panel discussion: Perspectives on quality of treatment and how can we work together in ensuring high quality of care and treatment

Speakers:
Ms. Tan Pei Lin, Malaysia
Mr. Rod Padua, Philippines
Team of Panelists
Take home messages:
*It is important in making sure the quality and safety quotient in generic drugs.*
*As a patient, what one can do to help ensuring the quality of generic is to voluntarily report any side effects of the drug to the country’s safety authority in the Ministry of Health.*
*Monitoring while on treatment in the region is crucial in making sure effectiveness of treatment is measurable regardless of drug (branded or generic).*

**Chronic Lymphocytic Leukemia Sessions**

In this year’s Rising Sun, for the first time, Chronic Lymphocytic Leukemia (CLL) sessions were included in the meeting’s agenda. Most of the patient groups in the Rising Sun network serve as the only blood cancer support groups in their local country. The addition of CLL education through Rising Sun will allow patient advocates to support this specific sub-group throughout the Asia Pacific Region.

This year’s CLL sessions started with introductory topics, and was conducted in 3 sessions:

**CLL Session 1**

The CLL session opened with a CLL 101 session, aimed preparing the participants for the CLL medical session by the speaker. Basic blood concept and CLL related terminology was discussed and refreshed.

**Speaker:**
Pat Garcia-Gonzalez, USA

**CLL Session 2**

CLL Session 2 introduced the participant to CLL as a blood cancer, the nature of the disease, the treatment options available and its prognosis, follow up and monitoring guidelines.

**Speaker:**
Dr Raymond Wong, Hong Kong

*Take home messages:*
*Participants were exposed to CLL, most of them were learning about this disease for the first time.
This session serves as a foundation to understand more about CLL related topics moving forward.*

**CLL Session 3**

CLL Session 3A focused on CLL in Asia Pacific and
3B on Characteristics, special circumstances, needs and supports.
Speakers:
Dr Raymond Wong, Hong Kong
Dr Haris Rahman, Malaysia

Take home messages:
CLL is currently viewed as an uncommon disease in the region, hence not receiving enough attention.
Limitation of local and regional data on the disease from the aspects of epidemiology and treatment outcomes.
There are similarities and differences of CLL compared to CML patient.
There is also relatively less research on CLL in the region.
Lack of patient groups and patient education are observed in this region.
Advocacy groups would play an important role in supporting CLL community, these roles including representing patient voices, form mutual support, advocates for new treatment options and clinical trials access, as well as education and awareness on CLL.
Capacity Building Session Highlights

Fundraising was identified as an area of focus for this year’s Rising Sun. Kristofer Rogers, a leading authority on online fundraising and social crowdfunding was our resource person for this important session titled Strategies and Donors Engagement of Fundraising. He also led and facilitated the workshop.

A total of four sessions were devoted to this topic. Participants were highly engaged with the workshop, actively taking part in brainstorming and group presentations. During the workshop sessions, Kristofer also used Rising Sun patient organization’s fundraising events as the case studies.

Each participant was given a copy of a workbook containing the workshop slides as well as an important glossary, prepared by Kristofer to facilitate meeting the needs of Rising Sun’s patient organizations.

Take home messages:
The interactive workshop highlighted many aspects of fundraising and helped participants to look inwards and come out sharing not only each other’s’ experiences but looking at various other avenues and improved skill sets in the area of raising “resources”.
Fundraising is not necessarily a big-scale event, and every successful fundraising attempt starts with small steps.
One key action of fundraising is the “Ask”. As a fundraiser this is the simplest as well as hardest thing to do.
To be innovative and creative in devising strategies and exploring uncharted territories is a vital skill that needs to be honed.
Presenting and showcasing the organization’s strengths in a convincing manner and documenting efforts and success stories is a vital tool.

Best Practice Sharing Overview

During this session, five best practices (chosen from projects submitted) were presented by the representatives of the respective groups. All five chosen projects showcased different aspects of advocacy and support activities within the CML community that were carried out by the respective organizations.

Every group was given 15 minutes for presentation, followed by 5 minutes to field queries from the delegates. This allowed everyone in the room to ask questions that are specific to their own needs.
Summary, Recommendations and Next Steps

The Rising Sun Meeting is viewed as a great opportunity for patient leaders from the Asia Pacific Region to come together with their common goals. The ongoing focus on education, advocacy and sharing of best practices seems to be well received by the community.

This year’s meeting was a big improvement compared to the previous meeting looking at these various aspects:

- The improved quality of discussion.
- The maturity of patient advocates.
- The shift from self-centered towards community-centered.
- The dedication and efforts of our speakers and
- The participation levels of the delegates – from interpersonal discussions to group involvement.

Medical topics in CML including those related to treatment access and monitoring, STOP treatment, coping with long-term side effects, as well as generics remain important topics of discussion among all global advocates. It is significant that these topics were being discussed in the context of their relevance in this region. Asia Pacific, including South Asia, remain very unique regions compared to the Western World. Hence these topics would need to be addressed based on regional needs, practicality, and suitability in accordance to the local or regional situation. Advocates and healthcare physicians are being reminded that patient safety remains a top priority in cancer care.

Fundraising remains a key need of all patient organizations, and it is important to continue to grow patient advocates’ capacity and expertise in this area. The workshop format, which allows participants to interact and brainstorm with each other, with facilitation from expert appeared to be more effective in knowledge transfer. It is recommended to keep this similar format in future meeting.

The Max Foundation, together with Steering Committee is recommending an impact assessment to be conducted in 2016 among Rising Sun groups, to quantify the current collective impact of patient groups in the region and to provide a baseline that would serve to identify gaps in services, as well as allow measuring changes in impact levels in the different areas of influence in the future.
Meeting Evaluation

Meeting Feedback Survey serves as an important resource for The Max Foundation and Steering Committee to collect input and continue to build befitting agendas for future Rising Sun Meetings.

This year’s survey information was collected from the participants on the following aspects:

- General feedback on meeting and the topics’ relevance to their work
- Time allocation for presentations and networking
- Content and framework for medical and patient advocacy (including capacity building) session
- Most valuable and least valuable aspects of this meeting

One of the very strong feedback messages was that 100% of respondents (34 respondents) said the meeting is valuable. 88% agreed that the topics discussed during this year’s meeting are relevant to their work in patient support and advocacy. These are the two strong indicators showing that Rising Sun Meeting is important for patient advocates in this region in support their work, building up their capacity and advocacy skills.

On the aspects of time allocation, 88% indicated that time allocation was enough for presentations; and 82% said that time allocation for networking was enough. It is recommended that participants make an effort to use the available time during face to face meeting to maximize interaction with other participants.

90% of the respondents indicated that they understood medical sessions well. It was also mentioned by a few respondents that speakers were very good and the new format (interactive CML 201) was great for medical-related topics. A few of the respondents also indicated that topics are excellent.

91% of respondents said the fundraising workshop was helpful for their advocacy work. A few of them suggested fundraising topic to be continued to be included in future meetings, and have groups to present fundraising projects as case studies.

When asked about most valuable aspects of the workshop, we received very encouraging response, indicating that they rated all sessions of the meeting valuable. Although the response from each of the respondents was varied, from the collective survey feedback, it was noted that all sessions received a mention.

For Rising Sun 2015, the survey results were overwhelmingly positive, showing that participants found the chosen topics useful and relevant, that they were happy with the format including time allocations, and that they found the sessions comprehensive and understandable. The participants acknowledged that continuous and back to back medical sessions in a day challenges their ability to focus their attention. This important participant feedback will be used as reference and guidance when we work on the subsequent Rising Sun Meeting.
Key highlights from Feedback Forms

- “Speakers were very good- should repeat them.”
- “I like the game show 201. Some of the days had too many sitting lectures. Incorporating engaging activity would help!”
- “Focus more case study on the advocacy session to make the session more interactive. The session in fundraising was well done.”
- “I love this session, could you have more sessions and working team about fundraising.”
- “Dinner with MaxSmiles member is the most wonderful part of RS 2015. CML 201 to refresh the terms which will be mentioned in meeting by playing game is good for us to understand the meeting in the following 3 days. I hope these 2 events again in Rising Sun 2016.”
- “Wonderful meeting!! The real cases of anything that advocates had done or had achieved - fund raising, care giving etc.”

Special highlights

The highlight of this year’s Rising Sun would be the off-site dinner hosted by a local patient support group, MaxSmiles, Thailand. The members of MaxSmiles spent months to plan and prepare this dinner and to welcome the participants of Rising Sun. All the food was cooked by the members themselves. The menu was specifically designed, to bring the best Thai cuisine, as a symbol of love to the delegates from around the world. That night, each participant tasted love and friendship through the loving gestures shown by the patient group!
Rising Sun is an initiative of The Max Foundation, with support from Max Malaysia team serving as official secretariat

Steering Committee for 2015 Rising Sun Meeting
Mei Ching Ong, The Max Foundation (Malaysia)
Viji Venkatesh, The Max Foundation (India)
Ebna Habib Md Shofiuor Rahaman, Bangladesh CML Supporting Group (Bangladesh)
Jung Ho Park, Zero Club (Korea)
Pramod George, Friends of Max (India)
Roderick Padua, Touched by Max (Philippines)
Yong Yoke Choon, Max Family Society Malaysia (Malaysia)

Special Thanks & Appreciation to Sponsors
Special thanks and appreciation to sponsors who have continuously supported us and made the 2015 Rising Sun Meeting possible.

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Novartis Oncology – Through a primary educational grant support

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