



Newsletter HIROBA 2010. May

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Proposal for Revision of Medical Expenses Refund System

NPO "TSUBASA"

We announced that we opened the campaign for revision of medical expenses refund system on Dec. 3rd, 2009. The campaign named "the Liaison for Advocating Revision" was organized by collaboration of three groups, "The Group of Myeloma Survivors Japan", "Izuminokai – the group of CML survivors and families" and "The MDS Liaison". We held a press interview on the same day as well. Many people read the articles about this campaign, we imagine.

There is no question that the refund system for large medical expenses has been relieved hundreds of patients. It is very helpful that anybody can receive a refund of the medical expenses that is over ¥80,100. Nevertheless, it's still hard to pay ¥80,000 every month. Besides, the upper limit on the self-pay has been getting higher and higher without any clear reasons.

We propose an urgent motion to revise the medical refund system toward more supportive one under such a bad economical situation. And this proposal is not only for cancer patients but also for any other patients with serious diseases. We realized its importance through activities hearing from thousand of patients for a long time.

"The Group of Myeloma Survivors Japan" points out a problem. Some drugs which are indispensable for myeloma patients but cost slightly under ¥80,100 can't be subject to refund. "Izuminokai" emphasizes that Gleevec saves their life, but it threatens their daily life because

of medical expenses the other hand. The representative of "The MDS Liaison" says, "We have to struggle with not only MDS but also payment for drugs right after the diagnosis. We eagerly expect quick new drug approvals but we have to be afraid of the price of them at the same time."

Here again, we advocate the need for revision of medical expenses refund system. Revision must be encouraging for all patients fighting with serious diseases. We need to know how to promote this campaign and make it succeed. "The Liaison for Advocating Revision" needs to collect your ideas, advices and opinions. We aim at " Better Future, No Financial Worry " for all patients all over the world

We are holding a panel discussion for the first step as following. We expect hearing opinions from many people.

May 9th Wed, 2010 (in the afternoon)

At Ibuka Hall , Waseda University

"To get the high-tech medicine for patients quickly"

Open panel discussion "The path to medical expense problem solution" (tentative title)

Sponsored by NPO Japan Clinical Research Support Unit and NPO Tsubasa

New Outlook for Cancer Treatment: On Participating in the 7th International Conference of CML/GIST Organizations

Report on New Horizons 2009



Mr. Hidehito Tamura

Association of CML Patients & Families IZUMI

Overview

New Horizons 2009, a conference of representatives from CML (chronic myelogenous leukemia) and GIST (gastrointestinal stromal tumor) patient and support groups, was held in Lisbon this past June 26th to 28th. I had the honor of participating in the event, and would like to report about the conference here. New Horizons is a conference that started in 2003 with participants from European and other countries, where they report their understanding of the diseases, the operation of organizations, current state of affairs in their respective countries, and so on.

The conference was great, and the fact that people with the same illness gather together from all over the world itself was incredible. There were three days of attending meetings, seeing in person and talking face to face. Meeting topics were immediately useful, such as those dealing with knowledge about the illness or organizational operation. I am extremely grateful to have been given such a wonderful opportunity.

I probably have missed more than a few things, but I want to stress that there was more to the actual conference. It is my intention to communicate what I experienced there for the sake of better operation of the patient group.



Below is my memorandum on the conference. Titles are originals.

26-1 Welcome

This year's world conference had the participation of 126 representatives from 49 countries, of which eight attended for the first time, including Lebanon, New Zealand, Tunisia, and Ukraine. The meeting was opened with reports on the current situations surrounding CML. Below is an excerpt in bullet points:

- 10-20% of patients have resistance or tolerance to imatinib
- Sleeping stem cells are considered a cause for minimal residual fraction
- Three ways to change the sensitivity are: conventional cytogenetic analysis, FISH, and RTQ-PCR
- To screen for any mutation, bone-marrow puncture is necessary once every two years, and RQ-PCR every three months
- There is only one way to check if sleeping stem cells have disappeared: cessation of medications
- PCR results may vary among different testing facilities; if the value has changed from the last results by one digit, it should be considered a significant difference; if the value has increased, do the test again
- There is an ongoing study to stop imatinib treatment in Australia
- ELN (European Leukemia Net) has also proposed a standard for evaluating the effects of treatment after the initiation of therapy, and suggested that appropriate methods of treatment should be chosen
- Third-generation drugs include: bosutinib, XL-228, AP-24534, DCC-2036, etc.



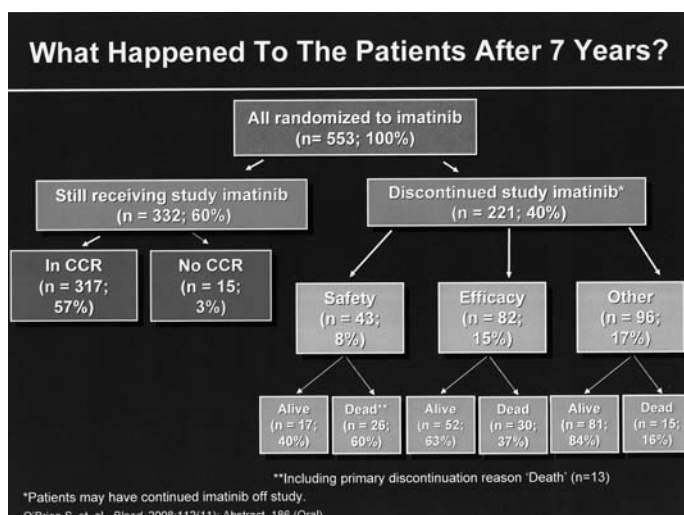
26-2 Building trust and confidence in cancer patient groups

- Governance equals input; input equals skilled work, management, funds, and governance
- Though its importance is often underestimated, management and control is indeed critical
- Three simple questions can draw answers to what the management control is:
 1. Is the organization doing the right things?
To make time to plan for the future; understand external environment; understand its tasks, understand funding; understand risks
 2. Is the organization conducting activities in the best way?
Whether or not the group is employing the best policy and methods; using time effectively at meetings; documenting issues appropriately; building effective team relationships; utilizing appropriate outsourcing
 3. Is the organization working with the right people?
Whether or not the organization is supporting committee members; controlling the activities of committee members; guaranteeing activities of high-level personnel; understanding skills and perspectives required by individuals; using modern search methods
- What challenges are you setting to control your organization? Do you have support and resources for these challenges?
- * I think it is important to have governance in an organization. How do you build it? There may be a number of factors, but I think it is the organization's policy that lies behind it. It is what the organization is centering on, and what it turns to as the criteria for judging its activities. Elements of the organizational operation may include leadership, communication skills, and personality.

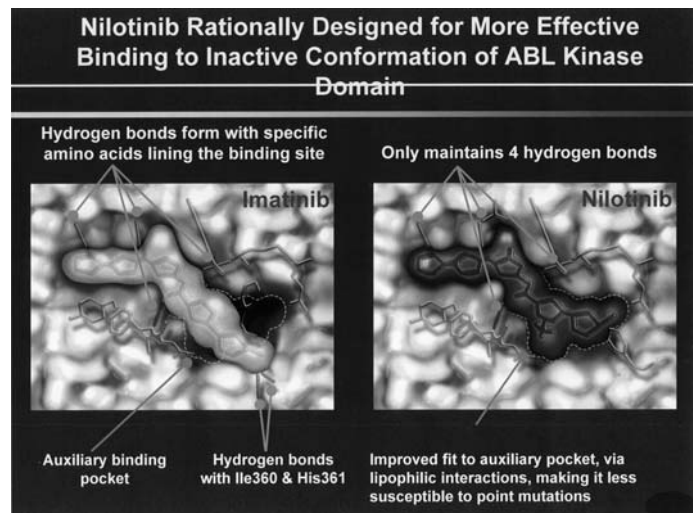
26-3 CML management update I

Where are we? Where are we headed?

- The initial IRIS study on CML (International Randomized Study of Interferon and STI571) and 7-year follow-up
- IRIS established imatinib as the standard prescription for chronic CML.



- The initial study had 1,106 enrolled subjects, about half of whom, or 554 subjects, currently remains in the follow-up study.
- Of the 554 subjects, 545 subjects (98.4%) are treated with imatinib. (Of these, 332 take 400 mg daily as the first-line, and 213 take it as a crossover from interferon/Ara-C). The remaining nine continue on interferon/Ara-C.
- Nilotinib is a logically-designed, highly selective, potent BCR-ABL inhibitor.
- Nilotinib has more flexible molecular alignment against ABL than imatinib, with about 30-fold efficacy.



27-1 CML management update II

- Sensitivity to mutation varies among different types of drugs
- Mutation analysis at chronic phase
- Is screening for mutation required in considering a second-line drug?
For dominant T315I mutation: a single-drug medication with a second-generation inhibitor has no role to play; allograft or experimental treatment should be considered
F317L: nilotinib is considered more effective than dasatinib
E255V/K: nilotinib or dasatinib in a standard dose may not be effective
Y253H: nilotinib is considered more effective than dasatinib
- T325I mutation
TKI prescription has its limits; third-generation TKI is currently being assessed
Other prescriptions: interferon, omacetaxine, etc. should be considered; transplantation is appropriate
- One should determine whether to increase imatinib or switch to a second-generation drug based on the duration of drug exposure and the remission status.
- * Whether or not there is way to completely cure CML is, for me personally, a very interesting issue. To answer this, it is necessary to discover the mechanism of sleeping stem cells. The lower rates of relapse among those who have had exposure to interferon before taking imatinib followed by cessation may provide a key. Testing quantitatively to measure the depth of remission with high precision is also desired. It is my hope for a further series of courageous

trials to continue and for the research and clinical setting to improve cure rates.

Cure CML

- Definition of complete cure of cancer can be expressed as follows:
[Time] x [Absence of symptoms of illness]
(Absence of symptoms of illness clinically or molecularly?)
- TWISTT = Time Without Symptoms, Therapy and Therapy-related complications
Duration of time without symptoms and treatment
- What is cure of CML?
- STIM (Stop Imatinib): project for ceasing imatinib
Started in July 2007, the project has 70 enrollees as of May 2009: patients with two year or longer continued molecular genetic remission. Among 34 patients who ceased to take imatinib for six months, 19 (56%) had relapse while 15 (44%) were in the state of CMR.
- Interferon is effective in killing early-stage Ph+ stem cells. This is probably why a favorable state after the discontinuation of interferon therapy is maintained.
- Interferon may have an effect to wake up sleeping CML stem cells.
- Ceasing imatinib may be possible in a few patients who have undergone interferon treatment in the past; however, its success rates or durations of remission remain unclear.
- Prior interferon therapy makes it easier for this strategy to be successful.
- Studies on interferon/imatinib have been conducted in France and Australia.



Mutation sensitivity (in vitro)

	Ba/F3 cellular proliferation IC ₅₀ values		
	imatinib (nM)	nilotinib (nM)	dasatinib (nM)
Native Bcr-Abl	280	13	0.8
M244V	2000	38	1.3
Q250E	1350	48	1.8
Q252H	1325	70	3.4
Y253F	3475	125	1.4
Y253H	>6400	450	1.3
E259K	5200	200	5.6
E259V	>6400	430	11
V299L	540 [†]	nd	18 [†]
F311L	490	23	1.3
T315A	971	61	129 [†]
T315I	>6400	>2000	>200
F317L	1050	50	7.4
F317V	350 [†]	nd	53 [†]
M351T	880	18	1.1
E359G	2300 [†]	nd	1.8 [†]
F359V	1825	175	2.2
V379I	1630	51	0.8
L387M	1000	49	2
H396P	850	41	0.6
H396R	1750	41	1.3

Legend:
 Sensitive (darkest grey)
 Intermediate sensitivity (medium grey)
 Insensitive (lightest grey)

O'Hare et al. Blood 2007;110:2242

27-2 Web communication, social media and patients

- On social media and communication among patients
- 45% of Europeans use the Internet.
 - For instance, Facebook, Twitter, and YouTube are utilized.
 - Facebook is an SNS (Social Networking Service) created for students in the United States. The service was initially restricted to student users, but it has been opened to the general public since September 2006. There one can post various classified ads or send direct messages to other users. It also allows users to upload photographs or videos (Facebook Video).
 - Twitter is a communication service for individual users to be connected by posting 'tweets'. Developed by the US company Obvious (currently Twitter), the service was started in July 2006. Twitter has a system that is halfway between blogging and chatting; individual users have their own site (home) and post a tweet within 140 letters in the form of the answer to the question "What are you doing?" Each one of tweets corresponds to a blog entry and is assigned a unique URL.
 - YouTube is a company based in San Bruno, California in the USA. It provides a video-hosting service on the Internet. One can use the service free of charge. It uses a technology called Ajax, and one needs to activate JavaScript to use YouTube. Most of the videos can be viewed without membership registration, though there are some that are viewable to members only.
 - Young cancer survivor networks
 - Every year as many as 70,000 people between the ages of 15-40 get cancer, and 10,000 of them have little probability of survival.
 - There has been no improvement in the five-year survival rates in the younger population since 1976.
 - One young cancer survivor network is "i2y."
 - Social media can connect strangers with one another, and help raise their awareness.
 - They can also strengthen roles of patient organizations.
 - A major advantage of the Internet is that it allows one to work on tasks at home. However, there are tasks that one cannot perform on his/her own, and it is important for him/her to find people who can help him/her, such as volunteers or those who share common interests.
 - Issues over SNSs include that one needs to exercise caution to avoid finding inaccurate or false information or when discussing delicate issues, and that one should not bring up religious issues, but handle creative issues.
 - One should not aim for something grand to begin with; he/she should start from ground zero and build up experience.

27-3 CML case studies

- During this session, several experts exchanged opinions on five case studies.
- For instance, Case Study #5 was a 65-year-old male Ph+ CML patient. He was prescribed 400 mg/day of imatinib,

and his Ph+ was 18% after six months of the treatment, and 12% after twelve months; what treatment would you give this patient? The blood concentration of imatinib was measured to be 560 ng/ml; what would you do to this? Also, this patient was taking a herbal supplement (St. John's wort) every day; what advice would you give him?

27-4 Interpreting clinical trial results

Lecture session on clinical studies from the standpoint of patients

- There are 150 trials underway worldwide.
- How are data on adverse effects evaluated?

28-1 Building strategic alliance in CML

- C. Jacobi: Patient groups should have relationship with front-line clinical doctors at a political level; it is important to work together with doctors
- M. Steagall (Brazil): Organizing workshops every two months; having 50 lectures available to view on the website
- P. Garcia Gonzalez: First, patients should gather together, and then invite doctors in, ensuring that doctors understand that they are partners; patient education is also necessary; nurses should bridge the two parties together
- M. Flielner: For 25 years, there was no system to collaborate with patients; with some organizations, it was not clear who their representative was, or which directions they are heading towards; there was also an obstacle due to language barriers



Participants discussion about building strategic alliances for CML

28-2 Spotlight on CML advocacy activities across the globe

There are approximately 40 CML patient organizations around the world. At the conference, presentations featured those from six countries.

<Australia>

- Every year sees approximately 250 new CML patients, many of whom fight their battle alone. They are encouraged to join the forum, which consists of a 90-minute session on the

theme of Talk Blood Cancer, intended to allow patients to share their experience with the same illness and support each other.

- For those who live in remote areas, there are groups that provide support over the telephone.
- CML telephone consulting is highly effective, not only for long-distance communication, but to people all over Australia.

<Latvia>

- Some 150 CML patients are in need of Gleevec.
- In recent years the government has not increased comprehensive financing for pharmacotherapy; the same goes for leukemia. Budget for health care service remains less than 3% of the GDP. A lawsuit was once filed, and there were both gains and losses.
- Only 30% of CML patients have been able to use Gleevec; the situation is similar in Poland.

<Brazil>

- There are about 5,000 CML patients.
- The treatment program was participated by 1,137, of whom 38 have subsequently died.
- 72% were treated with imatinib, 9% hydroxyurea, 7% transplantation, 4% dasatinib, 3% nilotinib, and 2% interferon.
- 74% had at least a day of missed dose during the previous month; 38% were forgotten doses, 34% for lack of the drug, and 4% was because they felt unwell.
- Data have been used to set the priorities at academic conferences of the ABRALÉ (Associação Brasileira de Linfoma e Leucemia [Brazilian Lymphoma and Leukemia Association]).

<Venezuela>

- In Venezuela, it is of high importance to secure funds to pay /pay for individuals.
- Most contributions are tied to respective programs, with regional and general administrative expenses left uncovered.
- 30 volunteers have been trained and became able to cater to patients' needs.
- New networks for hemato-oncologists throughout the country have been developed.

<Lithuania>

- 180,000 signatures have been collected on the Internet.
- Promoting public awareness is a key to success.
- It is necessary for patients to play an active role in place of doctors in the media.
- International support for patient communities is also necessary.
- Chance for CML patients to have access to imatinib was 16.5% in 2007, and 33% in 2009.
- Similarly, the change for GIST patients was 0% in 2007 and 100% in 2009.

<Canada>

- A 19-item questionnaire survey has been conducted on the web.
- Efforts were made to raise interest in the survey through press releases and international CML patient support groups.
- The Canadian CML association makes efforts to develop benchmarks for CML patients not only in Canada, but worldwide.
- 60% of patients are aware of the gap in information as to what should be done about CML-related economic burdens.



28-3 Meeting the challenge of adherence

Lecture on drug compliance

- Results from the ADAGIO Study were reported in the May 28, 2009 issue of Blood, regarding drug compliance.
- Medication practice was not followed as much as had been expected, prompting the necessity for routine checking.
- It is difficult for patients themselves to solve drug compliance issues.
- * Issues of drug compliance are not highly discussed in Japan, and it might have something to do with the nation's serious-mindedness.



All our dreams can come true — if we have the courage to pursue them

What I Saw and Felt as a Patient



Ms. Reiko Kamata
Japan Tsubasa Association

Introduction

I had a chance to attend the CML/GIST-related international conference called New Horizons in treating cancer held in Lisbon, along with Ms. Akiko Hashimoto, president of Tsubasa, and Mr. Hidehito Tamura, a representative of Izumi. The following is my own recount of the event.

During the three-day meeting, sessions covered a wide range of topics, illness/treatment-themes to discussions about working on challenges in leading a support organization. Simultaneous translation was provided in Japanese, French, Chinese, and Russian. At a conference such as this one where people from a number of countries gather and try to work together, I think it is highly important to ensure that participants from non-English

speaking countries are able to have an accurate understanding of what is being discussed and communicate their opinions unhesitatingly, without being affected by any language constraint. I think it was highly significant that they took measures with consideration to such a major issue as language barriers.

Discussions at Sessions

- Health care

With regard to topics related to illness and treatment, we had lectures from expert doctors on the latest treatment methods and data. I found it very meaningful that they addressed topics of high interest to patients. Of all, I was particularly impressed with the case study session led by three expert doctors, in which each of them shared their candid opinions. Furthermore, doctors and patients had active discussions as equals on such issues as future measures for cure and ways to build systems of collaboration with doctors, and I found it very encouraging, and leaving a strong impression.

- Operation of an organization

In the session about working on challenges in leading an organization, meanwhile, a range of suggestions concerning organizational operation were made in line with the situations of their respective countries. Particularly notable here was the

story shared by a European AIDS treatment group. They said they had been having influence over drug approval, by getting themselves directly involved in the planning of clinical trials, lobbying pharmaceutical companies, and monitoring adverse effects. It seemed really radical and interesting.

- International cooperation

Other than the sessions mentioned above, coffee breaks between sessions and lunch and dinner provided us opportunities for communication, and we, too, had a chance to have a talk with participants from many countries. We met people from China and Malaysia, and discussed that it should be meaningful to build deeper not only worldwide but regional ties as well. I think it will be wonderful if we can build a cooperative relationship among Asian countries. We also approached by some patients who had found us in a booklet that conference participants received, in which we introduce ourselves, complete with a headshot. That we had a chance to cultivate personal exchanges with individual participants made me really feel a person-to-person connection; it was heart-warming. Through our meeting with patients from all over the world, I realized everyone is facing their own illness, living strong, and acting actively. It was really inspiring.

I realized through this conference that, in addition to the chance to have first-hand access to highly sophisticated and technical information, networking is also very appealing, in that you come in contact with participants from countries around the world and share experiences or achievements, or discuss common challenges among different countries. Such an opportunity will help discover new potentials in patient support activities, providing a powerful force. As a patient, I felt extremely grateful to have a venue such as this.

Having come across a wide range of information during sessions or elsewhere, my trust in Japanese healthcare deepened. For instance, latest healthcare information is constantly obtained and passed on to patients, and we have advanced medical technology and healthcare settings, and a social insurance system. I had a renewed realization that such a state of healthcare which we enjoy and take for granted is in fact something we are extremely fortunate to have. There are surely a number of serious issues in Japan that should never be overlooked. Even so, it seems nevertheless reassuring to realize how reliable and secure certain things are, as we fight our diseases. Gaining various information can mean knowing something new, while at the same time giving us a good opportunity to re-examine how we perceive known facts.

About Myself

As a current patient of 17 years

I was diagnosed with CML in 1991 and received a bone marrow transplant from my younger sister in the following year. But I have since had repeated relapses, so I am still a patient to date. Since my diagnosis, I have received treatment

with two bone marrow transplants, donor lymphocyte infusion, Hydreia, interferon, Gleevec, and dasatinib, among others, so I can probably say that I have experience with essentially all major CML therapies since the 90s. I have also experienced a variety of adverse effects. Throughout this time, even the period between a therapy and a relapse, I have never been truly freed from the illness, not even for a moment.

After all this, I have felt and thought about a lot of things as a patient. Some thoughts would change from time to time, while others wouldn't. Even at the same moment, I might have contradictory thoughts intermingled, so my mind has constantly been plagued by all kinds of conflicts. What has remained unchanged in my mind ever since the onset of my illness, however, is that how important it is to have correct information, and how encouraging and necessary it is for patients to have cooperation with other patients and build a relation of trust with people who support us (i.e. families, doctors, nurses and other health care providers, friends, among others), in fighting our illness. It is because I found it significant that Tsubasa places an emphasis on providing information with support from various sources that I have been involved in activities at this organization.

As someone with such a background, what I have felt most strongly through my attendance at this international conference was that the way I fight CML changed definitively. In other words, while what used to be "a fight not to die" now seems to have become "a fight to live better" by all means.

In the past, being diagnosed with CML used to mean that your life would come to an end in 3-5 years unless you had a bone marrow transplant. Thus activities to establish a bone marrow donor registry were started in Japan, led by mothers who wished to save their children. A bone marrow donor registry was subsequently set up, and with an increasing number of registrants and advancement of treatment technology, the road for CML patients to survive has broadened widely. Bone marrow transplantation, however, is a gruesome and risky therapy, and even if one's life is saved, it is not unlikely for him or her to keep suffering severe complications or aftereffects. Meanwhile, there have been cases in which interferon therapy successfully maintains long-term remission, although there are issues of self-injection and adverse effects. Then came Gleevec, opening up the path dramatically for CML patients to live long-term, while leading a near-normal life. There still remain issues, of course, such as adverse effects, resistance, and substantial financial burden. For patients, there remains the hardship of having to suffer irrational pain, and this still needs to be solved. All the same, it seems to have made an enormous difference that what was once a fight fought solely for saving the life with a nearing death in view has transformed into one that aims to secure or improve one's life or the quality of life, now on the assumption that he or she will be able to survive for a long time. To me, it means that now we are able to live our life and

believe in possibilities for the future, without abandoning all hope.

- Fellows from around the World

Such was what made an imprint on my mind as I experienced the sessions and saw other participants doing their activities with strength and vigor at the conference. It was such a dynamic experience.

Now I look back like this: I think the conference showed us that knowing and cooperating could empower patients to face their illness and live stronger.

Patients suffering an illness are forced to make all kinds of decisions in all kinds of settings, and I think it will help us to know what we bear on our shoulders and what we must confront, in our making choices and taking measures that are right for ourselves. It has now become easy for patients to obtain information on various issues including the latest healthcare information, thanks to the advancement of the Internet, etc. To understand it correctly, however, you would need expert assistance. In the meantime, there are issues that are significant to patients even if they are not the center of attention in terms of healthcare, and having some forerunner patients who have already gone through such issues might help in dealing with them.

It may also be significant for patients to address directly to healthcare providers and communicate what we really need and feel about things, to build better healthcare and a better future.

Furthermore, telling stories about our own experience as a patient might allow us to share feelings with other patients, or present ourselves as a fellow or a forerunner to others suffering loneliness, which alone can be helpful. Patients are supported by many people. And yet, if patients ourselves could be of a help to someone, even if only a little, it will in turn empower us and help keep us alive. When I think of myself, I used to see myself as someone who could do nothing but be helped by other people. In addition, I remained uncured forever, despite receiving transplants twice. I thought I was only making other patients (especially those who have undergone transplantation) anxious, and I felt myself being good for nothing. It seemed that I should better stop having contact with other patients. Then I was made realize that there are patients who found it rather encouraging that someone like me, who has had so many relapses, could still be alive and well. This in turn became my salvation, and gave me strength. There were some patients at the conference who told me the same thing, and it was really encouraging to me.

I think that the existence of a countless number of our forerunners before us has made the foundation of medical advancement and thus supports us today. If we, too, can make our experience be of a help to someone else, it will be a further

encouragement to ourselves, helping us cope with our illness with more strength.

This also leads us to have a renewed realization that in order for patients to obtain a 'better treatment', links among patients ourselves and cooperative relationships with doctors and other healthcare providers are both important. Needless to say, patients' families and many other people who help patients in many ways are all essential, important beings, too. They all worry about the illness that plagues the patient, and share the same wish that he/she will be better. However, we all live different lives and have different backgrounds, and it is impossible for us to have an exact identical thought, even if you stand at the same position (such as a position as a patient), let alone among different positions. So it will be extremely important that we recognize what are common and what are different between one another, and strive to respect and understand with each other. Then, if we can work together hand in hand, this will become a significant force.

Conclusions

- Medical advancements and cooperation

As I have described above, I came back from the conference with a realization of medical advancement in every term. Not only the breathtaking progress in medications but the way how one fights his/her diseases has made truly strong developments. Such phenomenal developments have not only been possible because of patients' sincere wishes, efforts and endurance, but the existence of devoted providers of health care, those who engage in the research and development of medications to cure diseases, social understanding, and families and friends who heartily support patients. I could not help but think over this again. In order for patients to have support and live better in a true sense, I believe that we must trust and respect one another and work together.

- Drug discovery and trust

This international conference was held with the sponsorship of Novartis Pharmaceuticals. I've heard that Novartis takes a 'patient-centric' approach, and places a focus on understanding the needs of patients and building a better relationship with them. From the stage of preparing for the conference, we have spent a large amount of time with people from Novartis, and have talked and exchanged opinions throughout. Being given a chance to exchange opinions and communicate patients' voice directly with those who engage in the development of drugs that treat our illness, I think, was utterly meaningful, and made an extremely rare opportunity. Above all, it will be the most important to share a goal of 'having better treatment provided to patients' and build a trust-based relationship.

- In a beautiful town

Between our meaningful and fulfilling time at the conference, we had a chance to look around the town of Lisbon and its beautiful suburb Sintra, as well as Cape Roca that forms the

westernmost point of the Eurasia continent. Located in the westernmost part of Europe, Portugal has had Islamic influence and successfully accepted different cultures, through which it is said to have nurtured its flexible and generous culture over the period of its long history. Such a blend of different cultures and generosity was reflected in the atmospheres of the towns, buildings, and many artworks. It seemed to be a most appropriate venue for an international conference in which people gathered from many countries and aimed to realize differences among countries and their respective state of affairs, to learn from one another and adopt what is good from others, cooperate and work together to pursue happiness for all people.

It is my hopeful wish that patient support organizations all over the world will work together so that we can all face our illness with more strength, and that medical and pharmaceutical developments will further continue towards the goal of complete cure.



Communication filled with smiles during the conference period



Coffee Time

Akiko Hashimoto

I was filled with deep emotion during staying in Lisbon. A lot of people from all over the world got together for the CML international conference. Most of them were survivors of CML and they participated in their rolls vigorously and happily. It should far exceed my imagination that CML patients could enjoy their life by taking tablets, if I were in several years back.

I remember a conversation with friends when the Bone Marrow Bank Organizing Campaign reached the climax: "I wish we would talk smiling each other some day in a future like:

- Hey, I've got leukemia. I'm on medication.
- Oh, are you? Take care.
- Thanks! "

"Sure, it's our dream!"

We, then, understood it was an important key for patients to establish the Bone Marrow Bank under the control of the government. But at the same time, we were aware that it would be a burden for both donors and patients.

Upon opening the negotiation with the Ministry of Health and welfare, we agreed on the idea that the Bone Marrow Bank should be established with "cooperative spirit" so that it could help people understand what the Bone Marrow Bank was for. The goal of this campaign was sharing the dignity of "LIFE" among recipients, donors (as a volunteer) and all other people. That's why the campaign should not be combative. We often talked about it leading the campaign.

Various people participated to this conference – survivors who are on medication (Gleevec/Glivec), drug manufacturers, medical providers and supporters for patients. They looked enjoying talking

to other people. There was no barrier between them. Cooperative relationship was there. The time that different people cooperatively work with has come and it came faster than we expected.

I remember that an oncologist told me "How I wish, I could give people this drug traveling back in time people had to die because no possibility for the Hematopoietic Stem Cell Transplant". It was soon after that Gleevec was approved for the treatment of CML on 2001. So did I. Anybody who concern with CML thought so, I'm sure. And the other hand, anybody knows that Gleevec was brought by patients who struggled with cancer in the past, data analysis, development of computer technology and other social factors. The past brought "Now" and "Now" creates the future.

I celebrated my birthday in the middle of this trip. "I was born in a small town in Tochigi prefecture in Japan. I'm now aged enough to be called as an oba-san – a woman in late her middle age in Japanese. In the past, people used to think oba-san was too old to travel abroad – and now I am in Lisbon where is far from Japan". I had some kind of inexplicable feeling while I was looking the night view of the Lisbon from the balcony of the hotel after the conference and dinner. My heart was filled with a kind of deep emotion.

I wonder that cancer treatments and medical circumstances would be improved more than we expect some day in future. Nobody knows what kind of faces they would show us – it may be completely different or may be some improved framework. In either of them, I wish they are moderate and easy to use at any rate.

**Junko
Ohara**

- the 2nd series

A Hematologist of Tomorrow



“A Hematologist who manages to Understanding Medicine and the Most Advanced Medicine at the same time. It’s my Goal.”



Takahiro Shima

Born in Fukuoka pref. in Japan, here, 28 years,

Graduated the medical department of Kyushu University,

A graduated school student of the medical department of Kyushu University after working for the hospital of Hamanomachi and the Hematology Ward of Kyushu University Hospital.

The reason why I wanted to be a physician

A young boy dreaming to be a researcher gradually changed his dream to be a physician.

I was a boy who was very curious and eager to know anything by nature. For example, I wanted know the mechanism of its body when I found a bug, or I loved to know the mechanism of the machine and how it worked. This curiousness drove me to dream to be a scientists or a researcher. When I grew up to think of my future, I thought, “If I’m studying at all, I want to study something to help people”. Being a researcher or a scientist was my goal, but I wondered how much I could make sure what I did for the human world as a scientist. The other hand, I could see and confirm how much I helped people through studying modalities and elucidating the nature of the diseases. That’s why I changed my way to go from being a scientist to a physician.

I was absorbed in Kyudo (Japanese archery) in my college days.

I learned profundities of “spirit and skill” through Kyudo.

I wanted to join a club activity that is a kind of Japanese traditional sports and something uncommon. It was Kyudo. Kyudo values “Kata – basic movements” that has been built up and been refined through a long time. It’s not just a thing to understand at a moment’s notice. To get more refined skill, you have to face yourself, having insight into deep in your spirit, and keep practicing constantly. Spiritual strength is important for any sports. Especially in any Japanese traditional sports (Budo), You must understand the spiritual strength is the most important. The true victory must be accompanied with refined “Kata” and spirit. We call it “Shingi Ittai – the union of skill and spirit”. The medicine with the human touch has been demanded these days. Although I think there is no direct relationship between Kyudo and medicine, I’m sure practicing Kyudo helps me a lot to push forward understanding medicine.

Why a Hematologist?

I found the way I should go in the world of hematology which the clinical practice and study work together closely.

I wanted to go was the way as a researcher in my junior and high school days. But I have got interested in the communication with patients during the clinical training after the medical school. It’s a great encouragement to me to share the gratification of the successful treatment with patients. Even though I may face painful results that I don’t expect, I think it’s a work worth doing as one of medical providers. Besides, hematology is in the forefront of modern medicine. These factors led me to the way as a hematologist.

Hematology is a very difficult field both clinically and academically. Clinical practices directly connect with the most advanced medicine. For example, Gleevec that is one of molecular targeted agents was developed from a mechanism of gene that causes of leukemia and it tied together with the most advanced medicine. Now, there are many patients who enjoy their life by taking tablets. I think this is one of the remarkable characteristics of hematology, that is, the relationship between study and clinical practices is close and the results of the study are quickly applied for treatments.

I know the working condition for hemato-oncologists is never good in Japan. It would be same in any hospitals which fight with clinical practices with all their strength. I think the key to solve this terrible working condition is enough number of medical professionals in hospitals. Many hospitals have been struggling with a shortage of workers and it should be same in any other medical fields.

Communication with patients

Patients are fighting with cancer at the risk of their life. That’s why it’s important to make a bond of trust between patients and medical providers.

I saw many patients. They are all different. It may easy to have a smooth communication if the patient likes talking. It’

may hard to construct a good relationship if the patient is very shy to other people. There are patients who have to fight with a serious disease like a leukemia of which treatment itself is life-threatening, while there are patients who are expected to be successfully cured. The communication with them is obviously different in its difficulty. I used to worry and think how I should face to the patient who is distressed with the life-threatening diagnosis. Did he/she understand and accept my explanation? I wondered I talked to them with understanding words. Or I worried how the patient and his/her family spent the night after such a scary diagnosis. I used to reflect on the discussion with patients feeling some kind of pain. The pain was always with me whenever I had to do something difficult for patients.

Most patients are older than me. I'm still young and don't have enough life experiences like them, nevertheless it was my important task as a physician to build up a good relationship and talk closely with them. I know it's very important to make a decision accurately by scientific data, but it's also important to know the patients – their personality, background and so on. Knowing them well helped me make a decision, too. I often visited patients in their hospital rooms and talked with them including a small chat. I made it a rule to say “Any question? Do you have anything to ask me?” when I left the room.

Although it's just an impression without any grounds among physicians, we feel patients with more positive attitude towards treatments could overcome more successfully than patients who have less motivation to treatments. I know patients who are older than fifty years and overcame the hematopoietic stem cell transplantation. They are people with high motivation for transplantation, although they are not enough young to receive such a severe treatment. I found those people with high motivation had a good bond with physicians. They were never shy to tell us anything and this attitude helped us find early detection of complications or side-effects from treatments. It means that helping patients have high motivation is one of the keys to achieve a successful treatment. The best and adequate treatments are the most important, needless to say, but I think raising patients' motivation is another key. I would say, “Why don't you take a walk?” to a patient who does nothing but lying on the bed. I would say, “Well, how about walking along with me?” when he/she seems reluctant to do it and walk together in the ward. Raising patient's motivation to treatment and supporting by all people around the patient, this is the one that is called as “a team treatment”. No patient fights alone with his/her disease. No medical professional treats patients one-sidedly.

Going on to a graduated school

To make full use of knowledge after a profound study.

The more I got interested in clinical practices as a hematologist, the more I wondered what my goal was. The treatment for patients with hematologic disease has been advanced and got complicated more and more. I wonder how far I can trust the data collected by advanced examination technology. No error? If not, what is the margin of error like? These ideas worried me and I finally reached an idea that I

should not accept data from the laboratory without question. “I examine and watch patients carefully”. It'd become just an excuse if I don't understand data accurately. I was afraid that my outlook on patients got narrow because I focused on only things going with patients. I realized I had to cultivate the abilities to see the present state of treatment calmly. It pushed me to go on to a graduated school.

The subject of my study is the mechanism of hematologic disease. More effective treatment will be established when the mechanism of leukemia is elucidated. I'd like to make a profound study and make full use of it. Judging with objective and accurate view and using ability to grasp the patient's condition subjectively, I'd like to manage them at the same time in clinical practices in future. It's my everlasting theme as a hematologist.

My image of the ideal medical professional

I want to be a “cool ” physician who is admired by next generation.

Cardiac surgeons with the hands of God have lately been reported on TV. People would think of them cool and some of them would want to be a cardiac surgeon. As a result, we could have enough number of cardiac surgeons. It's same in the case of hematologists. If I could be a hematologist who is recognized to be cool by children, students and trainees, they might set on their goal at being a hematologist. So I want to be cool as a hematologist, as a human. I have actually admired senior hematologists who trained me when I was a trainee. All hematologists were respected by other medical specialists in the hospital where I had a training course as they said each other, “Why don't we ask hematologists when we have questions?” They were not just understanding toward patients but also very enthusiastic to study and research new treatments. They were all enthusiastic physicians and tried to do their best for patients. They used to research better treatments for patients until late at night and I think it is what medical specialists should be like.

Finally, let me tell something to you. It's a kind of a task to let patients have higher motivation toward the treatment. But the other hand, encouraging words from patients toward physicians as “Thanks!” or “Thank you for your effort” will be a great joy for physicians. Keep the motivation high and overcome the disease hand in hand!

... After the interview...

One of his favorite books is “ Silence” by Shusaku Endo. It is the book that was criticized by Christians and Christian churches all over the world including Japan. I think Dr, Shima who aims at the compatibility of understanding medical care and advanced medicine and Endo who kept trying to look deep inside of human spirit are standing on the same side. He is very charming with his smile. He is cool!



A Personality (A Pony)

A hard Worker loves Children smiling

Ms.Obana Ogawa (An America miniature horse)

[Profile]

Name	Obana Ogawa
Gender	female 14 years old (in a middle aged as a horse)
Native place	Nagano Pref. in Japan
Staples	Clover, fresh/dried grass
Favorite food	Apples, carrots and karinto (Japanese sweet cake)
Job	Communication with children, Giving children a ride
Membership	(NPO) Japan Leukaemia Research Fund (JLRF)
Family	The Ogawa (Kimiaki Ogawa who belongs to JLRF)

I'm Obana. People call me "Obana-chan", It's not totally different from "Obaa-chan (means very old woman in Japanese). Don't call me like that. I have a beautiful, white and long tail. It looks like the Japanese pampas grass called "Obana" in Japanese. My name comes from it.

I was born in a meadow in Nagano prefecture in Japan. I was raised up very healthy with other six siblings. I moved to Hachioji city in Tokyo with the Ogawa when I was seven years old. The new house I live in is far different from the house I used to live. It's small! It's in a community where is very crowded with houses and the road is all paved. You know, it's a kind of a big shock to me when I walk on the pavement. The neighbors got a big shock, too. A horse, even I'm much smaller than a thoroughbred, is walking in their neighborhood, just like a dog with his master.

Mr. and Ms. Ogawa patiently trained me to be friendly to neighbors and I learned how to be well-mannered to entertain people.

"Obana is well-trained and smart girl by nature. So, my wife and I trained her as a friendly horse to anybody who wants to touch or to get a ride on her back", said Ogawa.

Anybody thinks that horses love carrots. You, too, right? Yes, I like carrots. But the most favorite food is "karinto", that is a kind of Japanese traditional sweet. It's deep-fried and coated with brown sugar. My ears never miss the word "karinto". I can't help eating that sweetness.



“ She knows and understands the word [karinto]. She may understand what we talk, too. Because she shows the expression of “Oh, dear, I did something wrong” on her face when I tell her off. Attitude toward human is some like the between dogs’ and cats’. And IQ may be between cows’ and dogs’ IQ. She is curious, too” , said Ogawa.

My job is taking kids for a ride on my back. People call JLRF which my master belongs to. They want to have me for their events. I am often invited by the community promotion association around my place or schools for handicapped children. I also often join to a riding party at Tokyo University of Agriculture. Autumn is a festival season in Japan and I sometimes have to participate more than ten times in the festivals in many places. I’m a hard worker, right?

I have my hair shampoo before the event. I use the same shampoo with my master’s and he has my hair set for me after it. I love being pretty. I’m a girl!

I get to the place for the event by walking when it’s in the neighborhood, and Mr. Ogawa takes me by driving when it’s a little far from our place. I’ve never had carsickness. I love driving. I feel as if I were Pegasus while we are driving on the expressway.

I can give a ride to kids weighted under 30 kilogram. Adults and kids who are difficult to ride for physical reasons or are too young communicate by patting my back. Especially, handicapped children are looking forward to my visiting. Teachers tell Mr. Ogawa that kids have great expressions on their face which they never show usually and they become more active when I visit them. Some aged people recall their old days when horses used to be close to people.

I love basking in the sun doing nothing, but I’ll keep my activity for people who want to spend time with me. So, I’d like to visit more people. I don’t know if I could communicate with kids who are fighting with illness, but I could help siblings of ill kids release from their burden and feel happy.





A RELAY MESSAGE
NO.12



It's only one Wish " All Patients Achieve Victory for Well-being".

Tatsuo Hoshizaki

The representative of the Association of Myelodysplastic Syndromes(MDS)

■ My Friends who studied together to be a certified social worker

I resigned my job for a reason when I was 55 years old. It was before I received the diagnosis with myelodysplastic syndromes (MDS).

I used to work for a major firm which should be impossible to get a job without good academic background. My parents could not afford to expense of sending me to a university, nevertheless I was lucky to get a job in such a big firm and worked successfully until I got 55 years old.

I took a correspondence course in social welfare department at a university after resignation and aimed for a certified social worker. Studying at a university was my dream and I also wanted help young people who can't financially afford going to a university (or even high school) as a social worker.

I was helped by many people who studied together in my school life. They encouraged me many times. I think this experience led me to organize "the Association of Myelodysplastic Syndromes" that aims at structuring the networking with patients with MDS, medical providers, drug manufacturer and supporting groups.

It was not easy situation to a man past middle age to study as much as, as fast as, and as effectively as young people do. I had to know both will power and physical strength were declined. These handicaps were more severe than I expected. Attending to classroom instructions and a couple of works that were submitted every month were also hard to complete. But my friends helped me when I got in stuck. One of them was a young mother whose husband passed away. She has been raising three children up studying to be a psychiatric social worker. A girl in her twenties, her plan was becoming a care worker. Although she had cerebral palsy, she wanted to help other people whose health condition is more serious than her condition. A young boy, 19 years old, he dropped out his high school as a result of his terrible conduct. But he went back to a part-time high school and met a teacher who led him to think about going on to study more. His

goal was a teacher for handicapped children. A nurse used to attend classroom instruction right after a night shift in the hospital, nevertheless she never fell into sleep during the class. She used to say cheerfully, "My colleagues pushed me to go and study hard". Another one was a woman, in her 30 years, who regretted that she didn't find her husband was suffering from depression and could do nothing for him. Her husband committed suicide after that. She strongly desired to be a psychiatric social worker to help people struggling with various pains. I'm grateful to them for their help very much.

■ The life with MDS

I attended to a forum held by "Tsubasa (a supporting group for patients with blood diseases)" last fall. I saw many patients suffering from MDS and I got the latest information for MDS from several hematologists fighting with blood diseases with their patients. I also attended to the next forum and learned more about the latest treatment for MDS, such as the number of cases of the cord blood stem cell transplantation (CBSCT) has been rapidly increased among mainly older patients, the fact that even patients over 55 years can be applied for it, mini-transplantation as well. And I also learned the considerable effectiveness of chemotherapy without hematopoietic stem cell transplantation. I thought I could deliver this helpful information to patients who can't attend to these forums or patients whose situation is not convenient to get information. There are many people who have been devote themselves to support patients like Ms. Akiko Hashimoto (she devoted herself to organize the Bone Marrow Bank and the representative of Tsubasa as well). I could follow them and participate to something helpful for patients with MDS. My wish became stronger and I started making a networking that deliver the latest information on treatments of MDS.

Each patient has his/her own thinking way, each situation is different. But all Patients' wish is "cure and getting life back as they used to be". As for me, I'll devote myself to an activity for patients making full

use of the certification as a social worker (as a volunteer) when I overcome my disease.

I also would like to enjoy hot spring tours, playing baseball, tennis and skiing with my friends. Playing golf is also my wish when I get to 60 years old. Anybody has own dreams. Make it true. Don't give up! Join our network and find an effective treatment.

Although I didn't intend to hide this scary fact (diagnosis), I could not tell my wife and daughters about it for a while. I was just overwhelmed by such a scaring and unexpected diagnosis. Even I had never heard the name "MDS". Why me? What's going on with me? I looked for any information in desperation, hoping my doctor made a mistake, through the internet and medical books and I found it's a serious illness and it's a kind of life-threatening disease. I was frightened at the fact I knew and I could not think anything.

Only a few people around me knew the name of MDS, although it' has been reported more often on TV or other mass media about the Bone marrow Bank and Leukemia. I had to explain to let people understand it's seriousness – it's a kind of blood cancer that is a group of diseases that cause immature blood cells (called blasts) to accumulate in the bone marrow leading to a shortage of mature blood cells. It can also develop into leukemia. There is no cure for MDS except for hematopoietic stem cell transplantation so far.

■ With a hope

One day I got grateful news from my friends. They said they had registered themselves with the Bone Marrow Bank. One of them was told by his wife that she wanted him to wait the registration until their children got mature. But he said to his wife that anybody has possibility to need a donor for BMT (Bone Marrow Transplantation) and he didn't register spontaneously. Another friend said to me," I know the system doesn't allow me to give my stem cells to you directly, but I want to do it for you, if it's possible".

I read an article in the newspaper the other day. It said that the Ministry of Health, Welfare and Labor started out in quick approval of orphan drug (a pharmaceutical agent that has been developed specifically to treat a rare medical condition, the condition itself being referred to as an orphan disease) and it influenced drug manufactures to develop new agents. I'm sure the supporting network has been expanding. It's encouraging, but we should not rely on it. We should try hard by ourselves to solve the problems hand in hand.



Chronic Myeloid Leukemia (CML) / Myelodysplastic Syndromes (MDS) Joint Seminar “Coping with the Chronic Blood Diseases in Everyday Life”

Organized by the Nonprofit Organization Blood Disorder Information & Support Service, “Tsubasa” and the Association of CML Patients & Families, “Izumi”

Saturday, September 5, 2009

13:30 PM to 17:00 PM

Nagoya Sakae Gas Building Conference Hall

¥1,000 for Admission

Individual consultations by the physicians/presenters are available during the Seminar.

13:30 PM to 14:00 PM

Plenary Meeting

Facilitated by Akiko Hashimoto, Chief Director of NPO Blood Disorder Information & Support Service, “Tsubasa”

Keynote Lecture “Patient and Doctor Relationships — How to Discuss Issues and Cooperate to Get Through the Long-term Treatment” by Dr. Akira Hiraoka, Kenporen Osaka Central Hospital

14:00 PM to 17:00 PM

Section Meetings

A. CML Meeting

Facilitated by Hideto Tamura, Representative of the Association of CML Patients & Families, “Izumi”

1) Presentation and Discussion

Option 1: “Understanding CML and Upcoming Treatments” by Dr. Kunio Kitamura, Ichinomiya Municipal Hospital

Option 2: “Coping with Childhood CML” by Dr. Hiroyuki Shimada, Keio University Hospital / Chairman of the CML Committee, Japan Pediatric Leukemia/Lymphoma Study Group (JPLSG)

2) Panel Discussion “Being in an Age of the Novel Drugs”

Panelists: Dr. Koichi Miyamura, Japan Red Cross Nagoya Daiichi Hospital

Dr. Takaaki Takeo, Yokkaichi Municipal Hospital

Dr. Kunio Kitamura, Ichinomiya Municipal Hospital

Dr. Isamu Sugiura, Toyohashi Municipal Hospital

3) Sharing Experiences and Supporting Each Other

B. MDS Meeting

Facilitated by Akiko Hashimoto, Chief Director of NPO Blood Disorder Information & Support Service, “Tsubasa”

1) Presentation and Discussion “Understanding MDS and Deciding the Best Treatment Among Your Options” by Dr. Tomoki Naoe, Nagoya University Hospital

2) Panel Discussion “Present and Upcoming Treatments for MDS”

Panelists: Dr. Tomoki Naoe, Nagoya University Hospital

Dr. Akira Hiraoka, Kenporen Osaka Central Hospital

Dr. Masahiro Kizaki, Saitama Medical University Hospital

3) Overall Discussion by the participants, Dr. Hiraoka (Kenporen Osaka Central Hospital), Akiko Hashimoto (Cancer Telephone Information Service), and Tatsuo Hoshizaki (MDS Association)

発行・編集

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