

3rd EBMT Patient & Family Day

Saturday, 28 March 2009

Göteborg Convention Centre, Sweden



www.akm.ch/ebmt2009

Giving hope a chance

International experts will talk about new developments around haematopoietic stem cell transplantation and answer your questions.



Welcome

We are looking forward to welcoming patients and carers, including family and friends to the 3rd EBMT Patient & Family Day in Göteborg on Saturday 28 March 2009. This event is already a tradition and an integrated part of the annual EBMT meeting.

A positive, informed partnership between patient and doctor provides many benefits for both parties involved, not least increased confidence and trust. This is particularly important when there is a choice of treatment options. One of the mottos of this special day is therefore *"What my family and I wish we had known beforehand"*.

Furthermore, patient and family issues have become an essential part of the different EBMT activities aimed at improving stem cell transplantation (SCT) and cellular therapy. EBMT has contributed to the growing success of SCT for the past thirty years, and has proven to be a model for other scientific organisations.

In order to facilitate participation all sessions will be simultaneously translated into Swedish or English and the programme is designed to be spacious, thereby allowing plenty of time for questions and discussion.

For patients, families and friends, technical advances, new drugs and improvements in patient care are of vital importance. Treatment success however cannot only be described as surviving a serious disease, but also as having a good and rewarding quality of life. Building on the experience of previous years' meetings, the 3rd EBMT Patient & Family Day programme has been designed to bring up such issues.

The morning programme will address important questions regarding the integrity of the stem cell donor and the problems that may occur when two family members meet the challenge of a stem cell transplantation; one as a patient and one as a potential donor. The second plenary session will discuss the consequences of a cancer diagnosis for the patient's body image, and the frequently overlooked problem of genital chronic Graft-versus-Host disease.

After lunch, the difficulties of presenting complex information will be discussed under the heading of *"What my family and I wish we had known beforehand"*. Two patients will share their experience of the information given before transplant by their doctor. Their narratives will be commented on by two experienced transplant physicians. Contributions from the audience will be encouraged.

Later in the afternoon, simultaneous workshops will outline standard treatments, with special reference to news and pioneer developments in the field of autologous and allogeneic transplantation for leukemias, lymphomas and multiple myeloma.

One important aim of a patient organisation is to act as a pressure group and advocate the best treatment practice on a European, national and regional level. Strong patients' associations are beneficial for patients and also for caregivers at all stages. At this meeting, communication between patient associations within the field of hematology will be encouraged and facilitated, and at the end of the scheduled programme, facilities will be made available to enable meetings between representatives of patients' associations. It is hoped that this interaction will be the starting point for a closer cooperation between European organisations working on behalf of patients.

On behalf of the EBMT, and the organising committee, we have the pleasure to invite and welcome you to Göteborg, Sweden for an informative and fruitful 3rd Patient & Family Day.

Mats Brune
Congress President 2009

Christina Bergdahl
Chair / Swedish Blood
Cancer Association

Anita Waldmann
President / Myeloma Euronet

Dietger Niederwieser
EBMT President



Programme

- 09.00 – 09.10 **Welcome & Introduction**
*M. Brune (Göteborg, Sweden), C. Bergdahl (Skara, Sweden),
D. Niederwieser (Leipzig, Germany)*
- 09.10 – 09.20 **Overview of transplant activity and scientific trends**
Speaker: D. Niederwieser (Leipzig, Germany)
- 09.20 – 09.30 **Nurses role in care and science**
Speaker: E. Aerts (Zurich, Switzerland)
- 09.30 – 10.45 **Plenary Session 1: Protecting the interest of donors and patients**
Chair: A. Gratwohl (Basel, Switzerland)
- 09.35 – 10.00 **Protecting the integrity of the adult sibling donor**
Speaker: A. Kisch (Lund, Sweden)
- 10.00 – 10.10 Questions and discussion
- 10.10 – 10.35 **The purpose and importance of patients' associations**
Speakers: A. Waldmann (Ruesselsheim, Germany), C. Bergdahl (Skara, Sweden)
- 10.35 – 10.45 Questions and discussion
- 10.45 – 11.15 Coffee break
- 11.15 – 12.30 **Plenary Session 2: Effects of cancer diagnosis and treatment**
Chair: J. Apperley (London, United Kingdom)
- 11.20 – 11.45 **Cancer diagnosis, body image and intimacy**
Speaker: K. Bergmark (Stockholm, Sweden)
- 11.45 – 11.55 Questions and discussion
- 11.55 – 12.20 **Sexual problems and chronic GvHD after allo-transplant**
Speaker: E. Smith Knutsson (Trollhättan, Sweden)
- 12.20 – 12.30 Questions and discussion
- 12.30 – 13.30 Lunch break
- 13.30 – 14.15 **Plenary Session 3: What my family and I wish we had known beforehand**
Chair: E. Wallhult (Göteborg, Sweden)
- Patients and families' experiences, commented by transplant doctors**
Speakers: Two patients (to be selected), and two transplant doctors
(S. Lenhoff, Lund, Sweden and T. Kiss, Montreal, Canada)
- Questions and discussion



Programme

- 14.15 – 15.15 **Workshop 1**
Acute leukaemias
Chair: P.-O. Andersson (Göteborg, Sweden)
Speaker: J. Finke (Freiburg, Germany)
- 14.15 – 15.15 **Workshop 2**
Myeloma
Chair: S. Lenhoff (Lund, Sweden)
Speaker: U-H. Mellqvist (Göteborg, Sweden)
- 15.15 – 15.30 Coffee break
- 15.30 – 16.30 **Workshop 3**
Lymphoma, chronic lymphocytic leukaemia
Chair: E. Kimby (Huddinge, Sweden)
Speaker: H. Hägglund (Huddinge, Sweden)
- 15.30 – 16.30 **Workshop 4**
Chronic myelogenous leukaemia
Chair: H. Wadenvik (Göteborg, Sweden)
Speaker: J. Apperley (London, United Kingdom)
- 16.30 – 16.45 **Conclusions and Comments**
Chairs: A. Waldmann (Ruesselsheim, Germany), S. Lenhoff (Lund, Sweden), I. Andersson (Göteborg, Sweden), C. Bergdahl (Skara, Sweden)
- 16.45 **Networking Get-Together between European patients' associations**

All presentations will be provided in English and Swedish (simultaneous translation).

Organisation

Organising Secretariat

3rd EBMT Patient & Family Day
c/o AKM Congress Service
Association House
Freie Strasse 90
4002 Basel / Switzerland

Phone: +41 61 686 77 11
Fax: +41 61 686 77 88
E-Mail: info@akm.ch
www.akm.ch/ebmt2009

Registration

Please note no fee is charged to attend the meeting, but Pre-registration is required for planning purposes. May we kindly ask you to register by **February 24, 2009** with the enclosed registration form or online on the following website: **www.akm.ch/ebmt2009**

Sponsors

We thank our already confirmed sponsors for their generous support.

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Any further sponsorship is very much appreciated. For information, please contact the Organising Secretariat.