

EMBMTEASTERN MEDITERRANEAN
BLOOD AND MARROW
TRANSPLANTATION

NEWSLETTER

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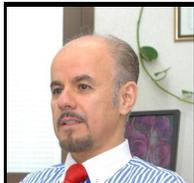
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Editorial Note, Mouhab Ayas, MD

After fifty years of research into the use of pluripotent hematopoietic stem-cell transplantation for cancer therapy, this procedure has evolved from one that was initially thought to be surrounded with insurmountable obstacles to a standard treatment not only for many hematological malignancies but for many hereditary hematological and non-hematological disorders such as hereditary bone marrow failure syndromes, immune deficiency disorders, metabolic disorders, and many others. Furthermore, more sophisticated donor sources and the astonishing advancements in supportive care have dramatically decreased transplantation-related mortality and improved outcome over the past decade.

Conversely, research has helped reduce the need for hematopoietic stem-cell transplantation in malignant diseases like acute leukemia (both myeloid and lymphoid) through the use of novel anti-leukemic agents and through the stringent application of risk-directed therapy in organized clinical trials which resulted in steady improvement in the outcome of those patients; gene therapy may one day totally eliminate the need for stem cell transplantation for patients with Fanconi anemia, severe combined immune deficiency, and list goes on and on and on...

So, the future will build on the past, and the possibilities for stem cell therapy seem limitless. The next 5 to 10 years will be an exciting time for transplanters as more and more is unlocked about the stem cell potential. One day, there may be more use for stem cells in regenerative medicine than there is in hematology / oncology.

EMBMT BUSINESS MEETING**EMBMT BUSINESS MEETING**

2 April 2012 (Monday)
Meeting Room, St. Moritz
Starling Hotel Geneva
Geneva, Switzerland

DATES TO REMEMBER

EMBMT Business Meeting
01-04 April 2012
Geneva, Switzerland

EHA
14-17 June 2012
Amsterdam, Holland

Medical News:

Cord colitis syndrome in patients who have undergone cord blood hematopoietic cell transplants (HCT) is not associated with acute graft-versus-host disease or other causes of diarrhea after HCT, yet is common for patients receiving this type of transplant as was reported in a study published in the *New England Journal of Medicine*. Among 104 patients who underwent cord-blood HSCT in that study, the cord colitis syndrome developed in 11 (10.6%). The 1-year Kaplan-Meier cumulative probability of meeting the case definition for the syndrome was 0.16. The median time to onset after transplantation was 131 days (range, 88 to 314). All patients had a response to a 10-to-14-day course of empirical therapy with metronidazole, alone or in combination with a fluoroquinolone. Five of the 11 patients (45%) had recurrent diarrhea shortly after discontinuation of antibiotics, and all patients who had a relapse had a response to reinitiation of antibiotic therapy. On histologic examination, all patients with the cord colitis syndrome had chronic active colitis, with granulomatous inflammation present in 7 of 11 patients (64%). The syndrome is relatively common and should be considered in appropriate patients with no other explanation for their diarrhea. More in: *N Engl J Med* 2011; 365:815-824. September 1, 2011.

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The EMBMT participants during the Quality Management Training Course at Dubai, UAE last June 29 to July 1, 2011. Among the countries who participated were, Saudi Arabia, Egypt, Iran, Jordan, Lebanon, Morocco, Oman, Pakistan and Tunisia.

On behalf of the EMBMT Group we would like to thank all the participants (Dr. Amal AlSeraihy, Dr. Mahmoud Aljurf, Dr. Mouhab Ayas, Mr. Morad Al Kaff, Ms. Rima Jammal, Dr. Fazal Hussain, Dr. Alaa Elhaddad, Dr. Mohamad Abdelmoty, Dr. Amir Ali Hamidieh, Dr. Mohammadreza Ostadali Dehaghi, Ms. Ashrafsadat Mousavi, Dr. Fawzi Abdel-rahman, Dr. Abdulhadi Alzaben, Dr. Ahmad Ibrahim, Dr. Mohamed Kharfan-Dabaja, Dr. Mohamed Rachid, Dr. Meryem Qachouh, Ms. Rahma Al Mahrizi, Dr. Nour Ben Abdeljelil, Dr. Natasha Ali, and Dr. Bilquis Mohiuddin) who have joined. We would like to encourage members to participate.

ISCDP: First HLA Registry in Eastern Mediterranean Region



PROF. AMIR ALI HAMIDIEH
Director of Iranian Stem Cell Donor
Program Center

Hematopoietic stem cell transplantation (HSCT) is being increasingly utilized as the only curative therapy for a variety of malignant and non-malignant disorders worldwide. Recent years have witnessed a progressive increment in the number of HSCTs, mainly due to the increase in the number of volunteer donors. More than half of allogeneic transplants use unrelated donor products. Studies comparing unrelated donor hematopoietic cell transplants to matched related donor transplants are now showing similar outcomes. 65 unrelated volunteer donor registries

from 47 countries and 47 cord blood banks from 28 countries are now listed on Bone Marrow Donors Worldwide (BMDW). HSCT has been performed in Eastern Mediterranean and Middle East countries over the years and has shown qualitative and quantitative evolution in these regions; however, in contrast to developed countries, HSCT from matched unrelated donors has not improved in developing states. In view of the notable decrease in the family size in recent years, the creation of such unrelated donor banks seems to be essential to overcome this problem.

Due to lack of unrelated donor banks in Iran and Eastern Mediterranean countries, the Hematology-Oncology and SCT research center in Iran submitted the unrelated bone marrow registry program to Tehran University of Medical Sciences 2 years ago. Currently, it has registered more than 2500 volunteer donors to assess HLA typing of all donors and recipients.

Dr. Amir Ali Hamidieh, Director of Iranian Stem Cell Donor Program Center, stated that ISCDP joined BMDW as the first HLA registry in



Eastern Mediterranean and Middle East on March 8, 2011 and now there is an opportunity to search information for accredited donors listed on BMDW.

The hope is that other Eastern Mediterranean and Middle East countries will establish donor registries, providing an enormous pool of potential donors for patients in the greatest need of bone marrow transplantation. However, physicians should always try to provide care to patients regardless of nationality, race, color, gender and sex across the world.

نجات یک زندگی

بانک اطلاعات اهدا کنندگان سلولهای بنیادی ایران

بدینوسیله به اطلاع کلیه افرادی که داوطلب ثبت اطلاعات خود در "بانک اهدا کنندگان سلولهای بنیادی ایران" هستند می‌رساند این بانک با هدف یافتن دهنده سازگار برای پیوند آن دسته از بیماران نیازمندی که فاقد دهنده سازگار در خویشاوندان خود می‌باشند راه اندازی شده است و آماده دریافت اطلاعات HLA شما می‌باشد.
از کلیه داوطلبین علاقمند دعوت می‌شود جهت شرکت در این برنامه خدایستاده به آدرس زیر مراجعه نمایند.

تهران خیابان کارگر شمالی سه راه جلال آل احمد بیمارستان دکتر شریعتی
مرکز تحقیقات هماتولوژی-انکولوژی و پیوند سلولهای بنیادی
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۰۲۱-۸۴۹۰۲۶۶۹
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Stem cell transplantation, a parent's perspective

From: BMT Unit, Sultan Qaboos University Hospital

We relate a story told by a mother whilst taking care of her infant daughter in the BMT Unit. The mother served as an attendant to her baby, an ardent observer in the care of her baby and now added to her CV a story teller.

Baby girl Y (her mother's name is Ms. B.) was diagnosed of SCIDS in November of 2009. She had her BMT in March 2010.

The mother started with "I was so happy to finally get a baby girl, so I prepared everything since I was in my 2nd trimester, and when I delivered I started to see her growing up as a beautiful girl full of life. That day onwards I made plans for her future.

BUT everything disappeared after the first three weeks of her life. Suddenly she started to have skin rashes which I thought was a simple allergy and it will just disappear after sometime. The rashes were persistent so we brought her to Al Nahda and there she was diagnosed of dermatitis. After sometime we observed that she was not responding to the treatment. We were then referred to SQUH Immunology clinic for further treatment.

One day I received a telephone call from SQUH telling me to bring my daughter to the hospital for admission and for more investigation. At that very moment, I refused to bring her and treated her according to the advices I was given at home.

Until one night, one Thursday night "I can still remember as if it happened only yesterday", my baby started to have foul smelling loose stools (4-5x a day) which caused her to develop a very bad diaper rash, she was also vomiting.

Hurriedly, we brought her to SQUH hoping that they can solve whatever problem she is experiencing right then.

When we got there, my baby was irritable and crying that I ended up crying with her for fear of the unknown and of losing my baby. She was suspected to have H1N1 and was isolated on 4-purple (H1N1 ward). That night I could not sleep, I felt like half of my body is drowning with fear and the other half is trying to be strong so she can depend on me

I kept on asking myself why her? She was a normal baby when she came into this world, she looks at me with wide

eyes showing me her innocence, and will she be able to tolerate all this? Will this not traumatize her for life? WHY?

Doctors and nurses were in and out of my daughter's room doing this and that. I was just there, trying to comfort my daughter, feeling numb, not understanding anything they are explaining to me, but one thing registered in my mind she was negative of H1N1.

Thank God, my hopes were up and finally I saw some light that soon my daughter will be alright but still my fear is kept at the maximum level for nobody has told me what is really wrong with her. I kept asking what disease is she having, where did she get this disease?

From the 4-Purple Ward, we were moved to 1-Purple (pediatric ward). Again I experienced another stress because more investigations were done. I felt like I was doomed for life. And then finally a bomb exploded in front of me, they told me my child suffers from Severe Combined Immune Deficiency Syndrome (SCIDS).

The doctors sat with us and aptly explained the disease to us, but deep inside as a mother I was trembling with fear knowing the pain and suffering she will undergo. I can feel and hear her small body screaming and asking me WHY? I felt so numb and helpless.

From the innermost depth of my heart, a strong voice tells me that there is hope for her, that for every problem, somewhere lays a solution. As her mother it is my job, my obligation to search for a solution. I shouldn't give up because this is the time she needs me most. I should be the source of strength, her

comfort and she should be able to feel that she can rely on me. They say that if a door closes, a window will open. BMT for my daughter was my window for this ordeal.

And so we went for counseling about this procedure. The pros and cons were explained to us. Together my husband and I sat and seriously talked about what we are about to submit our child into. It took us few days to finally decide that she will undergo BMT.

In January 2010, we were admitted in the BMT unit. As I entered the unit I was having mixed emotions. I felt sad because we were so isolated as if we are inside the jail, fear because so many instructions to be observed while we are in the unit. With an ounce of hope, we somehow were prepared to face anything for her.

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..... (cont)

Stem cell transplantation, a parent's perspective,

From: BMT Unit, Sultan Qaboos University Hospital

In the unit she received various medications including chemotherapy. It was during these times, that I experienced fear at the highest level... Imagine that small person receiving chemotherapy ... I thought I will collapse... that this is the end of everything...but the nurses were very supportive and calmly gave me the support I needed. For every touch my child receives from the doctors and nurses I can see how much they care for her. Somehow I found relief. For every question I ask from them they give me answers that somehow will suffice my waves of fear.

Then the BIG day came "BMT DAY", a new "BIRTHDAY" for my daughter. I had mixed feelings that day, I was scared and yet somehow happy that finally a new if not much a little hope for my baby. Pulling myself together I kept still during the transfusion, the doctor and nurses were with me in the room never leaving us and finally after 3 hours it got over smoothly.

After the transplant I thought everything is over but then there was more heart wrenching experience for her. I can clearly remember those days when Dr. Dennison comes into the room as if I am seeing a guy who is the bearer of bad news when I see him I would hold on to my chest and prepare myself for whatever news he will give me like the catheter is not working

because it is blocked, it got infected so another line insertion is required and the old one needs to be removed and much more- she had a total of 3 CVC line insertion during her BMT days all these under general anesthesia. I would always ask myself WHEN will this be over, Can I actually tell them ENOUGH she went through a lot already - am I allowed to say all this.

Finally we were told of the plan for discharge but I had to stay in hospital as my baby's nutritional status was still poor and she had to gain some weight. We were sent on "parole" from jail to 2-Blue (pediatric hematology ward) on 6/05/2010..... WAS THIS FREEDOM?

The road does not end here, till the day we were discharged from the hospital up to this moment the follow-ups still keep coming but during these times my anxiety is less.

In my experience I was able to survive the "STORM" I went through because of the supportive and caring attitude of my nurses and doctors.

I thank God for whatever happened and take this as a fruitful experience to share with my fellow mothers of children having to face maybe the same ordeal as we did.



Top : A glimpse of Sultan Qaboos University Hospital from where delegates from Oman were welcomed in the Quality Management Course in Dubai.



Left : Happy faces of the EMBMT Nursing Group members from Iran, Lebanon and Saudi Arabia during the EMBMT Business Meeting in Dubai, UAE. (left)