Nurses Group Paediatric Committee

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INTRODUCTION & OBJECTIVES

for Blood and Marrow Transplantation

The Paediatric Nurses Committee was established in 2008 within the Nurses Group of the EBMT. The committee is dedicated to improving the care of paediatric and adolescent haematology and stem cell transplantation patients. The main objectives are to promote, develop and share knowledge and experience between the paediatric nurses throughout Europe, developing countries and within the EBMT.

The main activities are:

EDUCATIONAL ACTIVITIES

Paediatric session during the Annual EBMT meeting in Frankfurt 2019

- Poor adherance is associated with more infections after paediatric haematopoietic stem cell transplant, Ahna Pai, United States
- Occupational status among adult survivors following allogeneic stem cell transplantation in childhood, Jeanette Winterling, Sweden

- Prepare and conduct the paediatric session at the EBMT Annual Meeting.
- Collaborate closely with the Paediatric Diseases Working Party on the annual Paediatric Meeting and Training Course for Paediatricians and Paediatric Nurses on HSCT.
- Encourage networking among European nurses.

Daphna Hutt (past) Chair: Hilda Mekelenkamp (current) Members: Teija Schröder, Marjola Gjergji

EBMT

European Society

219 contact nurses



32 countries

RESEARCH ACTIVITIES

- 1) BMT-ICU Collaboration: Safe transfer of patient from SCT to ICU
- Study closed beginning 2019
- Results presented in Frankfurt 2019 and Regensburg 2019
- Publication planned 2020

2) Specialized Paediatric and Young Adult Palliative Care Services in

- Report of current EBMT paediatric nurse studies: safe transfer from SCU to PICU, Eugenia Trigoso, Spain and Daphna Hutt, Israel
- Report of current EBMT paediatric nurse studies: specialized paediatric and young adult palliative care services in Europe, Hilda Mekelenkamp, Netherlands

Paediatric Diseases Working Party Meeting in Regensburg: Sickle Cell Disease, what are the curative options?



In 2019 the pediatric disease working party meeting was held in Regensburg Germany on 16-17th of May. The meeting focused on Sickle cell disease (SCD).

Local nurses: Gerald Collier and Christoph Bauer.

- Attendance: 25 nurses from 10 countries: Austria, Belgium, Finland, Germany, Italy, The Netherlands, Monaco, United Kingdom, Spain and Israel.
- 174 total, nurses & physicians
- The nurses program was varied with topics covering a general overview on SCD, supportive care on SCD with chelation therapy, transcranial

European Paediatric Hematopoietic Stem Cell Transplant Centers

- Study closed beginning 2019
- Results presented in Frankfurt and Regensburg 2019
- Publication planned 2020
- 3) Skin care project: Skin Problems in Pediatric Patients undergoing HSCT
- Survey among nurses was done and presented in Regensburg by Mihaela Hartmann (Vienna, Austria) 2019

ONGOING PROJECTS

Current practice in supportive care for pediatric HSCT: Position of the **PDWP** within the **EBMT**

Currently one article is published(1) and one in the process of preparation(2) to be published in BMT. In collaboration with PDWP, Pediatric Nurses Committee & Nurses Research Committee of the EBMT:

- 1. Nava, T., Ansari, M., Dalle, J. et al. Supportive care during pediatric hematopoietic stem cell transplantation: beyond infectious diseases. A report from workshops on supportive care of the Pediatric Diseases Working Party (PDWP) of the European Society for Blood and Marrow Transplantation (EBMT). Bone Marrow Transplant (2020).
- 2. Prevention of infection- ward isolation and sterility policy, nutrition, post-

Doppler scan and the special psychological burden in SCD patients. Transplant related issues as haplo transplants in SCD and skin problems. Pain in pediatric patients as well as pain in adults SCD patients was discussed. We were fortunate to hear a patient talk on her experience. Round table discussions were held.

Pediatric grant: Shari Noraiee (UK).

Midterm Focus Meeting on Non Malignant Diseases 2020

From July 8th-10th we had our virtual Midterm Focus Meeting on Non Malignant Diseases, with parallel nursing sessions, by IEWP, SAAWP, PDWP and Nurses group.

Participant were able to view 12 pre-recorded presentations focused on:

- Care for the Donor
- The information roadmap during HSCT
- Emotional (and physical) preparation for HSCT
- How to survive isolation during HSCT
- Looking back on HSCT
- Supportive Care

We had nice discussions during the live Q&A sessions. Between 13 and 43 nurses attended this live sessions and 21-59 Nurses viewed the prerecorded sessions.

discharge policy, vaccinations and Infectious diseases.

Skin Care Project

We work on a Delphi survey with the aim to create recommendations on prevention and management of conditioning related skin toxicity in paediatric HSCT patients.

We are looking for experts to reach consensus on this topic. Please provide us your experts in the field of treatment related skin toxicity!

We need your help! **TOPIC: SKIN TOXICITY** in Paediatric HSCT patients

- **AIM:** To create recommendations on prevention and management for treatment related skin toxicity in Paediatric HSCT patients
- WHO: The Paediatric Nurses Group
- WHOM ARE WE LOOKING FOR: Experts in the field of skin problems in paediatric patients
- WHAT IS YOUR JOB/TASK: to provide us the mail address of your expert
- FOR WHAT: so, we can purposeful send out our specific survey on treatment related skin toxicity

OUR Email-address: penuco@gmail.com

Next year a live Midterm Focus Meeting on Non Malignant Diseases will take place in Leiden, the Netherlands.

Paediatric Session Annual Congress Madrid 2020

- Visit the paediatric session on September 1st from 4-5 pm
- EBMT congress nurses group grants for best pediatric oral & poster

CONTACT



For further information don't hesitate to contact the Paediatric Committee members. Our e-mail: penuco3@gmail.com

www.ebmt.org #EBMT20Virtual