



**HNHCP**

Haematology Nurses & Healthcare Professionals Group

## **HNHCP Newsletter**

### **Introduction**

Welcome to the newsletter from the HNHCP. The group was formed in December 2014 to support nurses and other healthcare professionals through the rapidly evolving landscape of haematology and enable them to deliver optimal care to patients and support their families. In this newsletter we will report from our educational conference held in Zurich at the start of February and give you an update on the group's activities.

### **News**

#### **ITP Educational Resources**

We are now pleased to announce the launch of an educational resource and an online learning programme on Immune Thrombocytopenia (ITP). The educational resource is available in English and has been translated into French, German, Italian and Spanish. Hard copies are available by emailing [hemcare@hnchp.org](mailto:hemcare@hnchp.org) or the resource can be downloaded from our website at [www.hemcare.org](http://www.hemcare.org).

The online learning programme is available at <https://hcplearning.co.uk> or you can link to it via our website [www.hemcare.org](http://www.hemcare.org). This programme will complement the HNHCP educational resource on ITP.

The programme has the same format as the educational resource and includes further reading and support materials. At the end of each module there is a small multiple choice question paper and on completion a certificate will be available.

#### **Multiple Myeloma (MM) Education Resource & Online Programme**

The MM resources are available at the same platforms.



# HNHCP

Haematology Nurses & Healthcare Professionals Group

## Membership

Membership of the HNHCP is open to anyone working within the field of Haematology and details of how to become an individual or centre member is available on our website :

[www.hemcare.org](http://www.hemcare.org) or you can email us at [hnhcp@hemcare.org](mailto:hnhcp@hemcare.org)

## Facebook & Twitter

Please like our facebook page – Haematology HNHCP – or follow us on Twitter @hnhcp to keep up to date with news and activities within the group.

## EHA 2019 Amsterdam

We will be attending EHA in Amsterdam on June 13-16<sup>th</sup> . Please come and meet us at our stand if you are there. We are also delighted to be working with the patient advocacy groups at this meeting.

## Education Needs Survey

Thank you to all who completed our education needs survey – the results have been analysed and submitted for publication. We will use the information gained to develop resources for health care professionals working with Haematology patients.

**Educational Conference – Friday 1<sup>st</sup> – Saturday 2<sup>nd</sup> February 2019**





# HNHCP

Haematology Nurses & Healthcare Professionals Group

The 4<sup>th</sup> Haematology Nurses & Healthcare Professionals Group Educational Conference was held on Friday 1<sup>st</sup> & Saturday 2<sup>nd</sup> February 2019 in the University of Zürich, Switzerland.

The aim of the conference is to provide specialist nursing education and updates and help to promote the field of haematology nursing. This will help nurses and the other Healthcare Professionals in improving the care for patients with a malignant and non-malignant haematological disease.

The Educational Conference has demonstrated that it is extremely important to expand knowledge among nurses and other allied healthcare professionals. Accessibility is for as many healthcare professionals as possible is important to us so there was simultaneous translation in 3 different languages (German, French and Italian).



On Friday we opened with our keynote presentation on Fatigue by Dr Bram Kuiper looking at this unmet need and how we as healthcare professionals can help with it. Dr Kuiper introduced us to the Untire app which helps patients self-manage their fatigue. Dr Thorstein Schmidt followed by presenting on the importance of physical activity during treatment and its' positive impact on quality of life.

After coffee and croissants where participants had the opportunity to network, meet colleagues from around the world as well as meet our sponsors, we had a joint session with the Lymphoma Coalition – looking at the work of patient groups in the support and



# HNHCP

Haematology Nurses & Healthcare Professionals Group

education of patients, as well as their vital role in patient advocacy. Lorna Warwick, the CEO of the coalition gave an overview of the group, the resources it has available and presented results from their global survey which gives valuable insights into the challenges faced by patients. Guy Bouget gave us the patient experience, and while acknowledging that no 2 patients are the same he gave the attendees a powerful description of his journey and why he was motivated to form a patient group and how health care professionals and patient groups can work together. The final presentation in the session was by Natalie Dren and looked at the informed patient and what they need to act as effective managers of their healthcare. The need of patients to have more knowledge and information and to take a more active role in their healthcare and healthcare professionals communicating better leads to better patients outcomes.

After lunch Louise Taylor gave us an overview of haemophilia and a presentation on the exciting developments in gene therapy for haemophilia illustrated with case studies. We then had 2 very interesting presentations on Thrombotic thrombocytopenic purpura (TTP) from Tomasso Radice giving us an overview of the disease and Siobhan McGuckin looking at the role of the nurse in managing this rare and complex condition

We concluded the day with a session on Immune thrombocytopenia (ITP) with Drew Provan giving an overview and medical update detailing the new and developing treatments for ITP and Fiona Dooley speaking on the nursing challenges looking at the impact of the illness and its treatment on patients and their quality of life. We were honoured to have Mieke Budel present to give us the patient's perspective detailing her journey with ITP. We were delighted to be able to launch our online educational resources – details have already been given on how to access these resources.



# HNHCP

Haematology Nurses & Healthcare Professionals Group



On Saturday the day we started the day with 2 presentations on CAR T-cell therapy with Nathan Wolfensberger presenting the attendees with an overview of the concept and its applications. The challenges in developing “living drugs” were discussed and the need for interdisciplinary co-operation in dealing with the complexities of this therapy was highlighted. The nursing challenges of CAR T therapy programmes and the patient journey were detailed by Marlene Vercasson and the nurse’s role in helping them navigate this complex process was described.

New therapies like CAR T cells lead to challenges with financing and how to pay for them without bankrupting the health care system so Tilman Slembeck gave attendees an introduction to health economics to help them understand how the costs of new therapies are developed and how they impact on the care that we can and do deliver to patients.

The afternoon commenced with a presentation on the management of Febrile neutropenia by Catherine O’Brien detailing strategies to improve the management of this common complication which can cost €10,000 per episode. She presented a febrile neutropenia risk assessment tool for neutropenia which can identify patient who can benefit from GCSF prophylaxis. Tumour Lysis syndrome from Anna Gotz a side effect of treatment that needs prompt identification and poses a management challenge to nurses caring for Haematology patients undergoing treatment. Catherine O’Brien then gave us an update on venous access devices, reasons to choose certain devices and the new guidelines for management of all aspects of these devices commonly used in our patient population.



# HNHCP

Haematology Nurses & Healthcare Professionals Group

Sara DiCosmo presented on the haematology patient in ICU demonstrating the challenges posed by these patients with 2 case studies and ways of managing a seamless transfer of care between both specialities.

Ginette Balk and Eta Nabers conclude the day with a powerful presentation on nurses supporting nurses dealing with dramatic and traumatic events demonstrating their protocol for helping the team process and deal with the effect on the individual and the team

During the meeting we also had 3 satellite symposiums sponsored by industry. Amgen provided a symposium looking at Biosimilars in haematology and the critical role of the nurse. Janssen Pharmaceuticals sponsored a session on Multiple Myeloma and Jazz Pharmaceuticals provided a session on AML and the journey to transplant and beyond.

## **Save the Date**

Our 5<sup>th</sup> Educational Conference will be in Zurich on January 10<sup>th</sup> & 11<sup>th</sup> 2020. We look forward to seeing you there.

[www.hemcare.org](http://www.hemcare.org)

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