

THE COMPREHENSIVE HAEMOPHILIA CARE TEAM AND GENE THERAPY: CONTINUING THE PATIENT FOCUS

17:15–18:30 Wednesday 5 February, 2020

Mississippi Room, World Forum, The Hague



Satellite symposium held at the 13th Annual Congress of the
European Association of Haemophilia and Allied Disorders (EAHAD 2020)
5–7 February 2020, The Hague, the Netherlands

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CHAIR'S INTRODUCTION

Prof Frank Leebeek

Erasmus University Medical Center, Rotterdam, the Netherlands

Dear Colleagues,

It is with great pleasure that I welcome you to The Hague – the seat of the Dutch government and home to over 200 international governmental organisations.

International agencies and governments require their exponents to be excellent communicators in the same way that healthcare professionals need to be effective in conveying clinical information to their patients. As gene therapy progresses towards becoming a realistic treatment for haemophilia, this need for strong and clear communication becomes ever more important.

Our symposium tonight will examine this issue starting with the patients' perspective. What do patients expect from gene therapy? What are their fears? Mr O'Mahony, himself a haemophilia patient, will examine some of these questions. Gene therapy cannot yet be thought of as a 'cure'. Although clinical trials suggest individuals may be converted from a 'severe' to a 'mild' or non-haemophilic phenotype, patients will continue to require clinical monitoring, and

long-term durability of expression remains to be determined.

The role of the nurse practitioner and physician, reviewed by Lead Nurse Pollard and Dr Kampmann, respectively, in addressing these concerns and expectations will become increasingly important. They will look at how these vital cogs of a haemophilia interdisciplinary team will work with their patients to ensure their disease, and the burden it brings with it, can be most effectively managed.

We hope our symposium tonight will leave you with plenty to think about and if you have any thoughts, then you will consider raising them in our 'Fireside Chat' – where our faculty will come together to answer your questions.

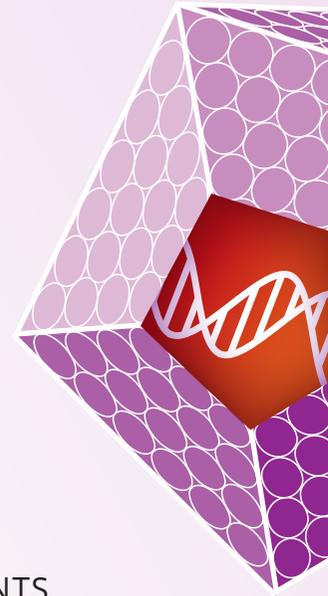
Yours sincerely,

A handwritten signature in black ink, appearing to read 'Frank Leebeek', written over a horizontal line.

Prof Frank Leebeek

AGENDA

- 17:15** CHAIR'S INTRODUCTION
Prof Frank Leebeek
- 17:20** PATIENT EXPECTATIONS, FEARS AND DECISION DRIVERS
Mr Brian O'Mahony
- 17:35** THE BRIDGE BETWEEN PATIENTS AND PHYSICIANS: THE ROLE OF THE NURSE PRACTITIONER
Ms Debra Pollard
- 17:50** ANSWERING YOUR PATIENTS' CONCERNS: HOW TO DISCUSS GENE THERAPY
Dr Peter Kampmann
- 18:05** FIRESIDE CHAT/Q&A
All
- 18:20** CHAIR'S CLOSE
Prof Frank Leebeek



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