Bloodline

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HFNZ

Bloodline

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Disclaimer: The information contained in this magazine is not intended to take the place of medical advice from your GP, haematologist, or specialist. Opinions expressed are not necessarily those of HFNZ.

The purpose of this magazine is to provide a wide range of accurate and timely information on all aspects of haemophilia and related disorders. Haemophilia is a dynamic specialty and therefore opinion may change or be varied from time to time.

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THE H WORD

I hope you are all keeping warm during these winter months. As New Zealand has progressively opened, so too has HFNZ. Planning for regional and national events is now well underway. We also have the results of our member survey, and the national council will be taking a good look at this to make sure HFNZ is delivering what members need.

As a council, we continue to pay close attention to the financial health of the organisation, for now and the future. We are so fortunate to have the continued support of the New Zealand public via Kiwifirst, generous benefactors, donors, companies, trusts and other organisations willing to support us financially. Times are tough out there for many, and I cannot emphasis enough our gratitude for this support. It really does make a difference to our community. I would also like to acknowledge the time of our volunteers. It is priceless in more ways than one!

Since the last edition of Bloodline, there have been opportunities to continue to connect with our global community despite the challenges of a global pandemic. I hope that many of you were able to attend the World Federation of Hemophilia's first global summit. Most of the content is still available to access free-of-charge online. There is also an opportunity to participate in the National Hemophilia Foundation's (NHF) bleeding disorder conference 2020. The NHF is the (much larger) equivalent of HFNZ in the United States. As you can see, events have gone borderless this year, so now is the perfect time to acquaint yourself with the global community and have direct access to the latest research and developments in care for people with inherited bleeding disorders.

Deon York

HFNZ President

From the CEO

BY SUE ELLIS

The last few months have been testing for us all as we navigated our way through the Covid-19 levels with Outreach Workers unable to meet members face-to-face. Instead, we've made more of an effort to check with members via technology – Zoom, phone calls, Facebook, and emails. With a return to some normality under Level 1, we can now look forward to reconnecting with members via face-to-face visits.

As we moved through the Covid-19 alert levels, we worked to maintain connections with members and with our supporters, and to plan events we knew could provide support under these unusual circumstances.

It was lovely to get so many responses to the **HFNZ Member Survey**. Congratulations to members Kathryn MacGregor and Brendan Lee for winning our Prezzy Card draw. A quick snapshot of the data shows that 98% of members are well aware of what HFNZ does to meet their diverse needs, both regionally and nationally, and value our national events. I was pleased to see that the Outreach service scored highly in providing access to services, up-to-date information, the amount of contact, and benefit for those contacts. Members are also satisfied with the way information gets to them via the website, Bloodline, Pānui, and Facebook with almost 100% of responses happy that the information is relevant, up-to-date, and reflects our community. However, there appears to be less satisfaction with our website.

CSL Behring Pharmaceuticals has kindly provided funding to help improve health outcomes for members through a redesigned and refreshed website. HFNZ has contracted a very experienced Wellington company to complete the update, and work is already underway.

In other funding news, I was very pleased to attend the national conference of the Buffalo Lodge, where the Franklin Lodge very generously donated $20,000 to HFNZ. This was a lovely surprise, and very useful at this difficult time.

Planning for the **Adult Weekend Workshop in Christchurch 6 – 8 November 2020** is well advanced. Thanks to Southern OR Worker Ross for taking the lead in the planning of this event with support from the team. The programme looks like it will provide an interesting and enjoyable experience for all, including workshop discussions, outside activities and the NZ premiere of the movie Bombardier Blood. For more info, see the piece later in Bloodline.

Planning is also underway for the **Youth Camp 28 April – 2 May 2021**, again led by Ross, with support from the team and valuable advice from Colleen McKay. This camp will be held at Blue Skies in Kaiapoi, North Canterbury.

As you may be aware, following the financial disruption of Covid-19, a decision was made by the National Council to postpone recruitment of an Outreach Worker for the Midland Region. In the meantime, Lynne and Amber are covering the Midland region, with the region split between them. For more information on this, check out the article later in Bloodline.

I want to acknowledge Amber and Lynne for taking on this extra work and the difficulty they have had tracking down members in the Midland region. I am very appreciative of them both for being quick to offer support for the Midland members, while continuing to look after their own regions, until we are in a better position to recruit an OR Worker for the Midland region again.

While it has been a difficult time for all of us to manage our work through the Covid-19 alert levels, the most important focus has been on ensuring members received the support and care they need. It is a great relief that we are now able to meet with members face-to-face and to enjoy a more relaxed environment to work in.

HFNZ CEO Sue Ellis attended the Buffalo Lodge National Conference to accept a generous donation

WFH Virtual Summit

On 14 – 19 June 2020 the World Federation of Hemophilia (WFH) ran their Virtual Summit. This online event replaced the World Congress, which had been planned for Kuala Lumpur. Unfortunately, the live event had to be cancelled due to the worldwide Covid-19 situation. Instead, WFH put together a fantastic online summit, featuring experts from around the world.

HFNZ President Deon York played a big part in getting the Virtual Summit up and running. He was part of the team who organised the multidisciplinary programme, as well as being a speaker. We also had HFNZ Youth delegate Lauren Phillips on one of the speaking panels. It's fantastic to see HFNZ people performing on the world stage.

One of the advantages of running an event like this online is that you can keep the sessions available after the live presentation has finished. This is particularly useful for us down here in NZ, as the sessions all started between 1am and 4am local time. Now you can access nearly every session from the comfort of your own home, at a time that suits you.

Once you're registered, you'll be directed to the login page, and from there to the Virtual Summit website.

The quickest way to find all the different sessions is to hover over the Sessions tab, and select Personal Agenda. Any session that has On Demand next to it is available to stream right now.

Here's a summary of all the sessions available, in the order they appear on the site:

WFH EDUCATIONAL: UNCERTAINTY IN AN ERA OF TRANSFORMATIVE THERAPY FOR HEMOPHILIA: ADDRESSING THE UNKNOWNS

Hemophilia is at the dawn of a new era in therapeutic management, one that can generate greater protection from bleeding and a functional cure in some individuals. The use of gene transfer is emerging as an effective long-term treatment for a variety of diseases. While clinical progress has been definitive, many questions remain unanswered as pre-licensure phase 3 clinical trials are underway. These unanswered questions translate into a state of uncertainty about the known unknowns and unknown unknowns intrinsic to any new therapeutic platform. This pre-summit session will examine the evolution gene therapy while addressing the unknowns that need to be answered.

SPEAKERS
Glenn Pierce - WFH
Megan Del Grosso - WFH

WFH GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA

This WFH session highlights what is new in the hot-off-the-press, 2020 WFH Guidelines for the Management of Hemophilia. Informed by the best available evidence and supplemented with expert opinion and patient preference, 4 key chapters of the WFH treatment guidelines will be featured in this session: hemostatic agents; prophylaxis; inhibitors; and treatment of specific hemorrhages. Come hear as the experts present updated recommendations and guidance!

SPEAKERS
Glenn Pierce - Vice-President Medical, World Federation of Hemophilia

To access the sessions, first you need to register. Just go here:
https://onlinexperiences.com/scripts/Server.nxp?LASCmd=L:0&AI=1&InitialDisplay=1&ShowKey=94278&ClientBrowser=0
and hit the Register Now button.

Cedric Hermans - Hematologist, UCL Saint Luc
Alok Srivastava - Professor of Medicine, Department of Haemotology, Christian Medical College
Steve Pipe - Professor of Pediatrics and Pathology, University of Michigan
Manuel Carcao - Co-Director, Hemophilia Clinic, Hospital for Sick Children
Margaret Ragni - Tenured Professor of Medicine and Clinical and Translational Science, Department of Medicine, Division of Hematology/ Oncology, University of Pittsburgh
Johnny Mahlangu - Professor of Haematology, University of the Witwatersrand and NHLS

WFH GENE THERAPY AND WORLD BLEEDING DISORDERS REGISTRIES

Two key WFH data programs are highlighted during this session: The WFH Gene Therapy Registry (GTR) and the WFH World Bleeding Disorders Registry (WBDR). With gene therapy for hemophilia on the horizon, there is an urgent need to develop a global database to monitor the safety and efficacy of all patients who receive gene therapy. The WFH Gene Therapy Registry is being developed to fill this need. This session focuses on the core data set of this registry and the global implementation plan. Additionally, a 2-year update of the WBDR is provided, along with an exciting announcement planned for 2020.

SPEAKERS

Barbara Konkle - Associate Chief Scientific Officer, WFH
Alfonso Iorio - Professor, McMaster University
Catherine Lambert - Cliniques Universitaires Saint-Luc, Haemophilia Centre

OPENING PLENARY

Please join us for the official opening of the WFH Virtual Summit: Connecting the Global Bleeding Disorders Community. The WFH President, Mr. Alain Weill, presents welcoming remarks, along with the WFH VP (Medical), Dr. Glenn Pierce, and the WFH's CEO, Mr. Alain Baumann, launching the first and exciting new initiative in bringing our bleeding disorders community together virtually.

SPEAKERS

Alain Weill - President, WFH
Glenn Pierce - Vice-President, Medical, WFH
Alain Baumann - Chief Executive Officer, WFH

MEDICAL PLENARY: GENE THERAPY

The promise of gene therapy is a single treatment ('one and done') that leads to steady-state expression of endogenous factor VIII or factor IX sufficient to achieve a functional cure (free of recurrent haemophilic bleeding) if not normalized haemostasis. Dr. Steve Pipe explores that, although we currently stand on the threshold of this achievement, delivering on this promise will require broad-based multi-stakeholder preparation with a focused emphasis on education, approval of safe and effective therapies, removal of barriers to access and excellence in clinical delivery.
Dr. Luigi Naldini continues to investigate new strategies to overcome the major hurdles to safe and effective gene transfer, and translate them into new therapeutic strategies for genetic disease and cancer. This has generated new insights into hematopoietic stem cell function, and the induction of immunological tolerance and tumor angiogenesis. Naldini presents his data regarding the further development of lentiviral vectors as a systemic gene delivery vehicle to complement the reach of AAV vectors.

SPEAKERS

Glenn Pierce - Vice-President Medical, World Federation of Hemophilia
Steve Pipe - Professor of Pediatrics and Pathology, University of Michigan
Luigi Naldini - Director, San Raffaele Telethon Institute for Gene Therapy

MULTIDISCIPLINARY PLENARY: WOMEN AGEING GRACEFULLY

This plenary, with special emphasis on women and those who care for them, aims to identify the issues that women with bleeding disorders may face as they age; this may include arthropathy associated with joint bleeds, increased fracture risk due to osteoporosis, gynaecological malignancy and the need for surgical intervention for cardiac disease. This remarkable panel of experts including, Dr. Michelle Lavin, Prof. Rezan Kadir, Dr. Jameela Sathar and Latifa Lamhene addresses womens' long-term health issues and improve screening, as well as answer any questions from the virtual audience.

SPEAKERS

Kate Khair - Director of Research, Haemnet
Michelle Lavin - Clinical Research Fellow, Irish Centre for Vascular Biology at the Royal College of Surgeons in Ireland
Rezan Abdul-Kadir - Consultant Gynaecologist, Royal Free London NHS Foundation Trust
Latifa Lamhene - Association Algérienne des Hémophiles
Jameela Sathar - Senior Consultant - Haemotology, Ampang Hospital

DENTAL TRACK: NEW TECHNOLOGIES, PSYCHOSOCIAL ASPECTS, AND INTERDISCIPLINARY DENTAL CARE

The Dental Committee is proud to present the dental track at the WFH Virtual Summit with a truly global representation of presenters, speaking on a broad range of topics related to the oral health of individuals with inherited bleeding disorders.

SPEAKERS

Lochana Nanayakkara - Part time Consultant, Restorative Dentistry at The Royal London Dental Hospital
Rebecca Schaffer - Adjunct Professor, A.T. Still University Arizona School of Dentistry & Oral Health (ATSU-ASDOH)
Zikra Alkhayal - Consultant Pediatric Dentist, King Faisal Specialist Hospital & Research Center
Laura Olan - Professor, Universidad Juárez Autónoma de Tabasco
Elvira Correa - Chair of the Oral Medicine/Dental Ambulatory, Hematology and Blood Transfusion Center, University of Campinas

REDEFINING PROPHYLAXIS IN THE MODERN ERA

The currently evolving novel therapies for the management of hemophilia has ushered in a new era characterized by improved prophylaxis targets and outcomes. In this session, the speakers redefine prophylaxis in the modern era by revisiting its definition, presenting data to support higher trough levels to achieve through prophylaxis, and introducing steady-state hemostasis as a possible new target for prophylaxis. The benefits of low-dose prophylaxis is also discussed.

SPEAKERS

Johnny Mahlangu - Professor of Haematology, University of the Witwatersrand and NHLS
Victor Blanchette - Hematologist, Hospital for Sick Children

Robert Klamroth - Director, Comprehensive Care Haemophilia Treatment Center & the Haemostasis & Thrombosis UnitVivantes Klinikum im Friedrichshain
Emna Gouider - Hematologist, Hopital Aziza Othmana

VWD, A CLOSER LOOK

Learn more about VWD and the perception of the condition throughout the world, how the WFH is working on it, psychosocial issues, the differences between men and women, and the treatment options available.
The session aims to answer the following questions: how is VWD perceived worldwide? What is the perspective of those who suffer it? Is there a difference between men and women?

SPEAKERS
Dawn Rotellini - Chief Operating Officer, National Hemophilia Foundation
Paula James - Professor, Queen's University
Jeannette Cesta - VWD Connect Foundation Inc.
Cody Kester - Board Member, Hemophilia Foundation of Arkansas
Baiba Ziemele - President, Latvia Hemophilia Society

Dental track: Dental Management and Treatment
The Dental Committee is proud to present the dental track at the WFH Virtual Summit with a truly global representation of presenters, speaking on a broad range of topics related to the oral health of individuals with inherited bleeding disorders.

SPEAKERS
Lochana Nanayakkara - Part-time Consultant, Restorative Dentistry at The Royal London Dental Hospital
Norjehan Yahaya - Specialist in Special Needs Dentistry (SND), Specialty Needs Dentistry Unit, Kuala Lumpur Hospital
Miryam Parreira - Dentist - Specialist in Surgery and Traumatology Bucomaxilofacial, Fundación de la Hemofilia
Daniel Sundaresan - Specialist, Special Needs Dentistry, Fiona Stanley Hospital
Mathew Lim - Alfred Health

INHIBITORS - THINK DIFFERENTLY

The development of inhibitory antibodies to therapeutic factor VIII (FVIII) in up to 40% of severe haemophilia A (HA) patients is the major complication in treatment/prevention of hemorrhages. The reasons some HA patients develop inhibitors while others do not remain unclear. This session summarises our understanding of anti-FVIII immune responses, the roles of T cells, both effector and regulatory, and generally discusses the interplay between FVIII and the immune system, both in the case of replacement therapy and in gene therapy.

SPEAKERS
Sébastien Lacroix-Desmazes - Team Leader, Centre de Recherches des Cordeliers, Universit Pierre et Marie Curie
Kathleen Pratt - Associate Professor, Uniformed Services University of the Health Sciences
Valder R. Arruda - Associate Professor of Pediatrics, University of Pennsylvania School of Medicine

MEDICAL FREE PAPERS: VWD & WOMEN'S ISSUES

Five of the best scoring abstract authors in category of the VWD and Women's issues have been selected to present their research. Each presenter is available for a Question & Answer discussion at the end of the presentations.

SPEAKERS
Andra James - Maternal-Fetal Medicine Specialist, Duke University Medical Center
Mandy Yap - MBBS(IMU), MRCP(UK), Clinical Haematologist of Ampang Hospital, Ministry of Health Malaysia
Mario von Depka Prondzinski - Director, Werlhof-Institute for Haemostasis & Thrombosis
Lubna Zafar - Consultant Haematologist, Fauji Foundation Hospital, Rawalpindi
Robert Sidonio - Pediatric Hematologist/Oncologist, Emory University
Roseline d'Oiron - Clinician Investigator, Centre Hospitalier de Bictre

TRM-201 (ROFECOXIB) FOR THE TREATMENT OF HEMOPHILIC ARTHROPATHY

Tremeau is focused on developing non-opioid pain therapy for patients with significant unmet need.

In this session you will learn more about our lead product, TRM-201 (rofecoxib), a COX-2 selective NSAID and a non-opioid analgesic. We also discuss our upcoming Phase III trial of TRM-201 for Hemophilic Arthropathy, which we plan to initiate later this year.

SPEAKER
Judith Boice - Tremeau Pharmaceuticals

ELEVATING PATIENT CARE IN HAEMOPHILIA – WHAT DO WE NEED TO KNOW AND WHY? - BY ROCHE

Our first symposium provides perspectives on what's involved in elevating patient care in haemophilia and why improving the level of care is necessary for the haemophilia community. We focus on the changing conversations around patient focused outcomes, the risk–benefit assessments of care, and recognising how stakeholders can facilitate joint decision making with patients. The symposium is comprised of pre-recorded presentations culminating in an open panel discussion illustrated with real-life examples of what can be achieved.

SPEAKERS
Mark Skinner - President, Institute for Policy Advancement Ltd.
Declan Noone - President, European Haemophlia Consortium
Johnny Mahlangu - Professor of Haematology, University of the Witwatersrand and NHLS
Jameela Sathar - Senior Consultant - Haemotology, Ampang Hospital

INVESTIGATIONAL AAV GENE THERAPY IN HEMOPHILIA: WOULD YOU BE READY? - BY BIOMARIN

BioMarin organized a symposium at the WFH 2020 Virtual Summit to foster discussion on potential clinical considerations for Adeno-Associated Virus (AAV)-based gene therapy for hemophilia, currently under clinical trial investigation.

The objectives of the symposium are to: discuss the science behind AAV-based gene therapy and potential practical considerations (including eligibility and follow-up after treatment) and to give insight into the perspectives of a patient advocate and a nurse through a live interview. Q&A is included at the end.

SPEAKERS

Wing Yen Wong - Vice President Clinical Sciences and Global Medical Affairs, BioMarin Pharmaceutical Inc.

Glenn Pierce - Vice-President Medical, World Federation of Hemophilia, Independent Consultant, La Jolla, CA, USA

Debra Pollard - Lead Nurse, Specialist Practice, Haemophilia, Katharine Dormandy Haemophilia & Thrombosis Centre, Royal Free Hospital, London, UK

Matthew Jajeh - Active Member, Hemophilia Foundation of Northern California, CA, USA

MEDICAL PLENARY: DIAGNOSIS

The combination of high BAT score followed by NGS-based genetic diagnosis could be the new paradigm for the primary diagnosis of IBDs. This needs to be followed by confirmation with functional haemostasis tests, as required. This approach will increase rates of detection of the known common disorders many folds and reduce the burden on these families towards accessing facilities for accurate diagnosis and appropriate treatment based on that.

SPEAKERS

Steve Kitchen - Clinical Scientist, Sheffield Teaching Hospitals

Alok Srivastava - Professor of Medicine, Department of Haemotology, Christian Medical College

Pierre Toulon - Hemostasis and Thrombosis Laboratory, Pasteur University Hospital

MULTIDISCIPLINARY PLENARY: QUALITY OF LIFE

This plenary seeks to explore and explain the role of pain in our lives. While pain is not something we generally wish to experience, it has an essential role in making us who we are. Lorimer Moseley will explore the new understanding of pain, and how that understanding can change one's perspectives of dealing with pain. "Sleep: Why we need it" gives an overview of what sleep is, how it happens and why 'good' sleep is so important to being healthy and how pain influences sleep patterns. Dr. Bajan Singh also offers ideas on how to promote good habits for better sleep.

HFNZ President Deon York spoke at the summit and helped organise the multidisciplinary programme.

SPEAKERS

Deon York - Board Member, World Federation of Hemophilia

Lorimer Moseley - Clinical Neurosciences, School of Health Sciences, University of South Australia

Bhajan Singh - Clinical Professor, University of Western Australia

CRITICAL NEED FOR HARMONIZED POST-MARKETING SURVEILLANCE IN GENE THERAPY

With regulatory approval of the first gene therapy product expected as early as mid-2020, there is an urgent need for a mechanism to collect long-term data on safety and variability and durability of efficacy. There will be elements required by regulators for post marketing surveillance and additional data needed to enhance our understanding of gene therapy outcomes and their impact on the lives of people with haemophilia. The aim of this session is to describe efforts underway by the American Thrombosis and Hemostasis Network and the World Federation of Hemophilia to collect long-term harmonized data and considerations of the European and US regulatory agencies, which will inform ongoing data collection.

SPEAKERS

Barbara Konkle - Associate Chief Scientific Officer, Bloodworks Northwest

Michael Recht - Chief Science Officer, American Thrombosis and Hemostasis Network

Caroline Voltz - Product Lead, Oncology, Haematology & Diagnostics Office, European Medicines Agency

Peter Marks - Director, Center for Biologics Evaluation and Research United States Food and Drug Administration

EMERGING FROM COVID - DEFINING A NEW NORMAL

This session explores what patients are most concerned about and what we should expect living in a Covid-19 world from the perspective of multidisciplinary healthcare professionals.

SPEAKERS

Declan Noone - President, European Haemophlia Consortium

Len Valentino - Chief Executive Officer, National Hemophilia Foundation

Kate Khair - Director of Research, Haemnet

Ed Kuebler - Advocacy & Leadership Programs Manager, Global Blood Disorder Foundation

LABORATORY SCIENCES TRACK: LABORATORY ISSUES AND TESTING

The advent of novel nonfactor therapies poses a new level of difficulty on the laboratory monitoring of these patients. It is important to understand the correct assays and the mode of action of these nonfactor agents. The WFH Laboratory Sciences Committee addresses these issues as well as monitoring replacement therapy.

SPEAKERS

Steve Kitchen - Clinical Scientist, Sheffield Teaching Hospitals

Stefan Tiefenbacher - Vice-President, Technical Director, Colorado Coagulation

Anna Lowe - Advanced Biomedical Scientist, Scientific Lead Haemophilia Programmes, UK NEQAD BC

Annette Bowyer - Senior Biomedical Scientist, Sheffield Teaching Hospital NHS Foundation Trust

Sukesh Nair - Professor, Christian Medical College and Hospital Vellore

LABORATORY SCIENCES TRACK: REPLACEMENT THERAPY AND TESTING

For decades the clinical laboratory has predominantly performed either manual or automated one stage (OS) factor VIII assays as a reliable means for monitoring factor VIII (F8) replacement therapy in hemophilia. The emergence of chromogenic factor VIII testing illuminated both discrepancies between testing methods and potential issues associated with product potency assessment. However, the creation of B-domain deleted recombinant (BDDR) F8 replacement product initiated the first real challenge for clinical laboratories to accurately monitor the advances in hemophilia replacement therapy. Currently, the escalation of hemophilia therapeutic advances, including extended half-life products (EHL), gene therapy and non-factor bridging therapies, have generated significant improvements for hemophilia management. However, the clinical laboratory may not possess the ideal laboratory test(s) for monitoring these new-age therapies, and it may be that a single F8 testing platform may not be adequate. A description of the EHL products and the optimal or acceptable laboratory F8 testing platforms is discussed.

SPEAKERS

Steve Kitchen - Clinical Scientist, Sheffield Teaching Hospitals

Emmanuel Favaloro - Principal Hospital Scientist, Institute of Clinical Pathology & Medical Research

Robert Gosselin - Clinical Laboratory Scientist, University of California at Davis Hemostasis & Thrombosis Center

Geoffrey Kershaw - Senior Hospital Scientist, Institute of Haemotology, Royal Prince Alfred Hospital

SUBSTITUTION THERAPY

Despite significant paradigm shifts in the medical management of hemophilia A with inhibitors and the expanding use of novel non-factor therapies, FVIII-based immune tolerance induction (ITI) is still the only effective means to inhibitor eradication. With the recently introduced Atlanta protocol, emicizumab prophylaxis is given in combination with 50-100 IU/kg FVIII three times a week. The session explores the impact of emicizumab prophylaxis for non-inhibitor patients and examine the current status of clinical studies regarding emicizumab prophylaxis.

SPEAKERS

Alok Srivastava - Professor of Medicine, Department of Haemotology, Christian Medical College

Midori Shima - Professor of the Department of Pediatrics, Nara Medical University

Robert Sidonio - Pediatric Hematologist/Oncologist, Emory University

Gallia Levy - Vice President and Global Head of Rare Blood Disorders, Roche Pharmaceuticals

Steve Pipe - Professor of Pediatrics and Pathology, University of Michigan

WFH EDUCATIONAL: PATIENT FOCUS: ASH, ISTH, NHF, WFH GUIDELINES ON THE DIAGNOSIS AND MANAGEMENT OF VWD

Join us for this patient-focused preview of two of the recommendations resulting from the international collaboration to develop guidelines for the diagnosis and management of von Willebrand disease (VWD), ahead of publication later this year. Learn why international clinical guidelines are particularly important to this community, how they were developed, and the important contributions of various stakeholders throughout this process.

SPEAKERS

Paula James - Professor, Queen's University

Nathan Connell - Chief of Hematology, Brigham and Women's Faulkner Hospital

Mark Skinner - President, Institute for Policy Advancement Ltd.

HEMOPHILIA B: CARE ACROSS THE SPECTRUM - BY CSL BEHRING

This symposium highlights the paradigm shift in hemophilia B treatment and management. Specifically, the discordance between disease severity and bleeding phenotype is reviewed. Defining sub-groups in the hemophilia B population who are currently undertreated will shed a light on the needs of the whole community. Additionally, the importance of high circulating FIX trough activity levels is discussed. Finally, utilizing digital tools based on robust pharmacokinetic principles has the potential to guide treatment strategies. New electronic tools will allow precision dosing that address the goals of both health care providers and patients to optimize outcomes.

SPEAKERS

Flora Peyvandi - Professor of Internal Medicine, Angelo Bianchi Bonomi hemophilia and Thrombosis Center, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Universit degli Studi di Milano

David Lillicrap - Professor, Department of Pathology & Molecular Medicine,Richardson Laboratory, Queen's University

Cedric Hermans - Hematologist, UCL Saint Luc

Alfonso Iorio - Professor, McMaster University

WFH EDUCATIONAL: TREATMENT CHOICE IN AN ERA OF CHANGE

This session explores the patient and provider perceptions on treatment choices: how does each make a choice and process the risk-benefit analysis.

SPEAKERS

Glenn Pierce - Vice-President Medical, World Federation of Hemophilia

Johnny Mahlangu - Professor of Haematology, University of the Witwatersrand and NHLS

David Page - National Director of Health Policy, Canadian Hemophilia Society

Brian O'Mahony - Irish Haemophilia Society

PHYSICAL ACTIVITY FOR JOINT HEALTH AND WELLNESS

Exercise joint and muscle can reduce spontaneous bleeding in the long term. Many patients focus only getting enough treatment products, which is impossible for developing countries. Musculoskeletal care is one solution. This session aims to demonstrate easy and practical methods in musculoskeletal care from orthopedist, physiotherapist and patient perspectives, including bone health without surgery, rehabilitation vs wellness, best patient practices.

SPEAKERS

Paul McLaughlin - Haemophilia - Physiotherapist, Royal Free Hospital

Adolfo Llinas - Orthopedic Surgeon, Fundación Santa Fe de Bogotá

Pamela Narayan - Executive Committee Member, Medical Advisory Board Member, Hemophilia Federation of India (HFI)

Chavez Edgecombe - Bahamas Hemophilia Foundation

WFH EDUCATIONAL: BETTER DATA, BETTER PATIENT OUTCOMES: 20 YEARS OF DATA COLLECTION

This workshop is intended for healthcare professionals engaged in clinical research and patient leaders and organizations who have an active interest in using health data in their work.

SPEAKERS

Part 1: Data Collection at WFH - Welcome

Ellia Tootoonchian - Data Specialist, World Federation of Hemophilia

Donna Coffin - Director, Research & Public Policy, World Federation of Hemophilia
Mark Skinner - President, Institute for Policy Advancement Ltd.
Part 2: 20th Anniversary of the Annual Global Survey
Ellia Tootoonchian - Data Specialist, World Federation of Hemophilia
Alfonso Iorio - Professor, McMaster University
Part 3: Improvements/New Approaches in Metrics
Ellia Tootoonchian - Data Specialist, World Federation of Hemophilia
Jeff Stonebraker - Associate Professor, North Carolina State University's Poole College of Management
Emna Gouider - Hematologist, Hopital Aziza Othmana

MUSCULOSKELETAL TRACK: SYNOVITIS AND SYNOVECTOMY

This session addresses the current understanding of synovitis and its treatment options with specific emphasis on chemical and radioactive synovectomy, surgical options, rehabilitation and non-surgical management.

SPEAKERS

Sébastien Lobet - Physiotherapist and Researcher, Clinique Universitaire Saint-Luc
Eline van Bergen - MD PhD Candidate, Van Creveldkliniek
Sylvia Thomas - Hematologist, Federal University of Rio de Janeiro
Mauricio Silva - Medical Director, Orthopaedic Institute for Children

WHAT DOES QUALITY OF LIFE MEAN TO YOU? LIVING WITH (AN INHERITED) BLEEDING DISORDER IN A CHANGING WORLD

Quality of life for patients is a topic often discussed among clinicians. This session focuses on what quality of life means from the perspective of a person living with a bleeding disorder. This session asks you to consider: what does quality of life mean to you, especially during a pandemic?


HFNZ Youth Delegate Lauren Phillips spoke at the Summit.

SPEAKERS

Deon York - Board Member, World Federation of Hemophilia
Nathalie Roussel - Assistant Professor, University of Antwerp
Cathy Harrison - Advance Nurse Practitioner, Sheffield Haemostasis & Thrombosis Centre
Lauren Phillips - Youth Committee Member, Haemophilia Foundation of New Zealand
Randall Curtis - Hemophilia Utilization Group Study (HUGS)

WOMEN AND GIRLS WITH HEMOPHILIA

The aim of this session is to address issues on women and girls with hemophilia (WGWH) integrating here female carriers with low levels of FVIII or FIX and/or bleeding experiences. The key points that will be covered are the importance of early diagnosis during childhood of affected girls, the management and treatment of the bleeding risk despite a large variability in phenotype expression, the joint health and the way to secure both maternal and fetal bleeding risks during pregnancy, delivery and the post-partum period.

SPEAKERS

Roseline d'Oiron - Clinician Investigator, Centre Hospitalier de Bictre
Sarah O'Brien - Pediatric Hematologist-Oncologist, Nationwide Children's Hospital
Andra James - Maternal-Fetal Medicine Specialist, Duke University Medical Center

EXPLORING THE WFH ELEARNING PLATFORM: OVER 700 FREE RESOURCES AT YOUR FINGERTIPS

A Guided Tour of the WFH eLearning Platform: Join WFH Educational Materials Manager, Fiona Robinson, as she shows you how to get the most out of the >700 resources and 24 languages on the WFH eLearning Platform. Together you will navigate the bleeding disorders themed eLearning Centres, explore the enhanced Featured Tools including many of your favourite well-loved WFH publications, and master the searching and sharing functions of the Platform.

SPEAKER

Fiona Robinson - Education Materials Manager, World Federation of Hemophilia

HEALTHY LIVING

This session discusses the strategies for healthy living in all developmental stages and share advice on nutrition, fitness, getting a good night's sleep, building self-confidence/self-esteem, healthy aging, and sexuality.

SPEAKERS

Sabrina Farina - Social Worker, Gulf States Hemophilia & Thrombophilia Center
Hariyati Shahrima Abdul Majid - Chief Health Psychologist, Naluri Life
Richa Mohan - Consultant Clinical Psychologist & Director, Empowering Minds Society for Research and Development
Mina Nguyen-Driver - Associate Professor, Oregon Health and Science University (OHSU)/ The Hemophilia Center of Oregon

MUSCULOSKELETAL TRACK: HOT TOPIC DEBATES

This session features three controversial topics debated by experts in their field: POCUS image capture by patients; Ankle Arthrodesis or Arthroplasty; HJHS vs. functional measurement.

SPEAKERS

Adolfo Llinas - Orthopedic Surgeon, Fundación Santa Fe de Bogotá
Hortensia de la Corte Rodriguez - University Hospital La Paz, Madrid, Spain
Annette von Drygalski - Director, Hemophilia & Thrombosis Treatment Center, University of California San Diego
Mauricio Silva - Medical Director, Orthopaedic Institute for Children
David Dalstrom - Orthopedic Surgeon, UC San Diego Health
Janaina Bosso S. Ricciardi - Physiotherapist, Hemocentro UNICAMP
David Stephensen - Physiotherapist, Kent Haemophilia Centre / Royal London Hospital

VWD

Von Willebrand disease (VWD) is the most common inherited bleeding disorder. This session provides an overview of VWD diagnosis and treatment, special considerations in treating women with VWD, and current genomic approaches to VWD. Diagnosis of VWD begins with the clinical assessment for the bleeding phenotype, and then made by laboratory investigation. Interdisciplinary management of childbirth and prophylaxis in the postpartum period are needed to reduce the risk of postpartum haemorrhage. Genomic approaches to VWD can inform VWD diagnosis, treatment, test assay selection, reproductive planning, and family counseling. Next generation sequencing is rapidly being adopted to provide more comprehensive VWF sequence information for patients with known or suspected VWD.

SPEAKERS

Jill Johnsen - Associate Member, Bloodworks Northwest Research Institute

Michael Laffan - Professor of Haemostasis and Thrombosis, Centre for Haematology, Department of Medicine Imperial College

Jameela Sathar - Senior Consultant - Haemotology, Ampang Hospital

ELEVATING PATIENT CARE – FIND OUT HOW TO CREATE YOUR 'NEW NORMAL' - BY ROCHE

Our second symposium provides practical examples of how to apply the theory from symposium #1 in improving patient care and the realistic expectations of the community. Our expert panel engages in discussion focused on the evolving needs of patients, effective collaboration between all stakeholders, and the importance of shared decision making when selecting treatments. Throughout the programme the panel highlights the tangible opportunities that exist for enabling patients to improve the level of care they receive.

SPEAKERS

Mark Skinner - President, Institute for Policy Advancement Ltd.

Declan Noone - Professor of Haematology, University of the Witwatersrand and NHLS

Johnny Mahlangu - Senior Consultant - Haemotology, Ampang Hospital

Jameela Sathar - Senior Consultant - Haemotology, Ampang Hospital

MANAGEMENT OF HEMOPHILIA IN TIMES OF UNCERTAINTY: ADAPT, INNOVATE, EVOLVE -BY PFIZER

We are living in an age of uncertainty due to the current global crisis. There is an increased need to adapt the way we work, develop innovate new therapies and to evolve our approaches to the delivery of care.

Now more than ever, in an era of transformative medicine, it is fundamental that information is shared with patients and patient communities, in order to support shared decision-making based on open, and transparent education.

Through a basic overview of the science underpinning gene therapy, this session explores the evolution of the patient-physician relationship.

SPEAKERS

Thierry VandenDriessche - Professor, Vrije Universiteit Brussel

Wolfgang Miesbach - Professor, University Hospital Frankfurt, Haemophilia Centre / Department of Haemostaseology, Medical Clinic 2 / Institute of Transfusion Medicine

Laurence Woollard - Director, On The Pulse Consultancy

WFH EDUCATIONAL: DIGITAL TECHNOLOGIES AND PERSONALIZED CARE TO MANAGE JOINT HEALTH

This session provides an overview of the cellular effects of bleeding in a joint and discusses the importance of individual monitoring plans for the preservation of joint health in patients with haemophilia. It also conveys the concept that every bleed matters and that treatment should be without delay and provided examples for how digital tools can enable education and collaboration with patients and the wider multi-disciplinary team to strive for zero bleeds.

SPEAKERS

Angela Forsyth - Director, REBUILD Program, Diplomat Specialty Infusion Group

Len Valentino - Chief Executive Officer, National Hemophilia Foundation

Deon York - Board Member, World Federation of Hemophilia

Alfonso Iorio - Professor, McMaster University

MUSCOLOSKELETAL FREE PAPERS: ORTHOPEDIC ISSUES

Four researchers will present their findings in the arthroplasties.

SPEAKERS

Adolfo Llinas - Orthopedic Surgeon, Fundación Santa Fe de Bogotá

Cedric Hermans - Hematologist, UCL Saint Luc

Jenny Y. Zhou

Ozgür Mert Bakan

Kumiko Ono

WFH EDUCATIONAL: CONNECTING THE GLOBAL COMMUNITY THROUGH PARTNERSHIPS: WFH TWINNING PROGRAM

SPEAKERS

Deniece Chevannes - Director of Health Promotion and Evaluation, Hemophilia of Georgia

Jayson Stoffman

Niamh O'Connell

John Sarmenta

Luisa Durante - Director, Programs and Education, World Federation of Hemophilia

GENE THERAPY: THE UNFOLDING STORY

We are still learning about Gene Therapy. Each patient experience is different, and gene therapy is not for everyone – either by choice or by exclusion because of the antibodies. What can we expect if we ARE eligible – what is it like to participate in the gene therapy trials? What is it like to be a patient once you have gone through the treatment? What if it does not work for me (one and done) – can I try other future therapies?

SPEAKERS

Debra Pollard - Lead Nurse, Specialist Practice, Haemophilia, Katharine Dormandy Haemophilia & Thrombosis Centre

John Pasi - Professor of Haemostasis and Thrombosis, Barts and the London, Queen Mary, University of London

David Page - National Director of Health Policy, Canadian Hemophilia Society

Garrett Hayes - National Youth Leadership Institute (NYLI) Representative, National Hemophilia Foundation

Rob Schroeder - Senior Executive Rep, Oncology-Prostate, Astellas

Enrique David Preza Hernandez - Federación de Hemofilia de la República Mexicana

PSYCHOSOCIAL TRACK: TRAINING AND CAREER GUIDANCE FOR YOUTH WITH BLEEDING DISORDERS

This session explores the ways in which social workers can assist youth with bleeding disorders explore careers and develop skills that will prepare them for employment. The presentation also addresses the economic disparity in countries around the world, which significantly impacts the opportunities that are available for youth with bleeding disorders, discusses how the bleeding disorders community has addressed this issue, and suggests ways that we can expand our efforts.

SPEAKERS

Susan Cutter - Social Worker, Hospital of the University of Pennsylvania, Penn Comprehensive Hemophilia Center
Claude Bartholomew - Social Worker, Providence Health Care (Adult Hemophilia Program)
Annie Bole - Lectures and Programming Assistant, Faith Justice Institute
Tony Roberts - Registered Educational Psychologist, South African Haemophilia Foundation
Santosh Manivannan - Chairman, Youth Group of Hemophilia Federation (India)

MANAGEMENT OF COMORBIDITIES IN BLEEDING DISORDERS

With the introduction of clotting factor concentrates in the early 1970s, significant improvements in quality of life and life expectancy of persons with hemophilia (PWH) were realized. Unfortunately, as a result of transmission of HIV and hepatitis C virus (HCV) by contaminated concentrates in the 1980s, many of these gains were lost. Now with four decades of PWH unexposed to contaminated factor products and current treatments capable of suppressing and eliminating HIV and HCV, respectively, the survival rate is once again increasing. In addition to the usual comorbidities associated with advanced age in the general population, several specific issues occur in patients with bleeding disorders. This session explores the incidence and management of the comorbidities of the ageing PWH with a focus on cardiovascular disease and osteoporosis.

SPEAKERS

Mike Makris - Professor of Haemostasis and Thrombosis, Sheffield Haemophilia and Thrombosis Centre Royal Hallamshire Hospital
Pal André Holme - Professor, Senior Consultant, Oslo University Hospital
Christine Kempton - Associate Professor, Hematology & Medical Oncology, Emory University Hospital Midtown

MEDICAL FREE PAPERS: YOUNG RESEARCHERS

The top six abstracts from young researchers as selected by the Abstract Review Committee are presented and compete for the Christine Lee Haemophilia Journal Award in this Young Researchers Free Paper Session.

SPEAKERS

Cedric Hermans - Hematologist, UCL Saint Luc
Geertje Goedhart - Epidemiologist, HemoNED Foundation
Patricio Cesar Gatti - Assistant Professor, Surgery Department, University of Buenos Aires
Sandeep Albert - Associate Professor, Department of Orthopaedics Unit-1, Christian Medical College and Hospital Vellore
Tien-Truong Dang - Ozlem Turan
Glaivy Batsuli - Assistant Professor of Pediatrics, Emory University

PSYCHOSOCIAL TRACK: NEW COMMUNICATION STRATEGIES FOR THE BLEEDING DISORDERS COMMUNITY

This session explores challenges that affect communication between HTC team members and the patients and families whom they serve. As providers, we know what we want our patients to understand, but sometimes, it seems that we just cannot get our message across effectively. These experiences can be frustrating and, in some cases, can result in strained relationships between patients and providers. In this session, we discuss common communication barriers and ask participants to identify situations that they personally have found difficult or frustrating. By the end of the session, participants specify one or two communication skills that they want to utilize or improve and identify resources to assist in this process.

SPEAKERS

Ed Kuebler - Advocacy & Leadership Programs Manager, Global Blood Disorder Foundation
Silvina Grana - Psychologist, Fundación de la Hemofilia de la Argentina
Diane Standish - Faculty, Partners in Bleeding Disorders Education Program of the Indiana Hemophilia and Thrombosis Center
David Silva - Spanish Federation of Hemophilia
Patricia Cabré - Therapeutic Pedagogue, Catalan Association of Hemophilia

MEDICAL FREE PAPERS: LATE-BREAKING 2

Four non-scientific abstracts were selected to present on research in registries, psychosocial, prevalence and tele-dentistry.

SPEAKERS

Saliou Diop - Board Member, World Federation of Hemophilia
Ampaiwan Chuansumrit - Director, International Hemophilia Training Center - Bangkok
Silvia Riva - Senior Lecturer in Psychology, St. Mary's University
Ahmad Tarawah - President, Middle East and North Africa Hematology League
Alison Dougall - Academic and Clinical Dental Consultant, Dublin Dental Hospital

MULTIDISCIPLINARY FREE PAPERS: DATA COLLECTION AND PATIENT OUTCOMES

Three speakers from the WFH Research & Public Policy department present on three key projects: The World Bleeding Disorders Registry; Data Quality; and the Annual Global Survey.

SPEAKERS

Mayss Naccache - Gene Therapy Program Manager, World Federation of Hemophilia
Emily Ayoub - Data & Research Manager, World Federation of Hemophilia
Toong Youttananukorn - Data & Research Coordinator, World Federation of Hemophilia
Ellia Tootoonchian - Data Specialist, World Federation of Hemophilia
Johannes Oldenburg - President, German Society of Thrombosis and Haemostasis Research

GENERAL PLENARY: MANAGING COVID-19 AND BLEEDING DISORDERS

Since the outbreak of the coronavirus disease 2019 (COVID-19) there has been an unprecedented global public health challenge. This session - developed as an educational response for the global bleeding disorders community - presents four main topics:

- **Radoslaw Kaczmarek** focuses on the pathophysiology of COVID-19
- **Flora Peyvandi**, MD, explains the clinical manifestations of COVID-19
- **Cedric Hermans**, MD, provides practical advice on the management of COVID-19
- **Mark Skinner** concludes the session with information on the safety and supply of plasma derived products during the pandemic.

SPEAKERS

Cedric Hermans - Hematologist, UCL Saint Luc
Radoslaw Kaczmarek - Postdoctoral Research Associate, Hirszfeld Institute of Immunology
Flora Peyvandi - Professor of Internal Medicine, Angelo Bianchi Bonomi hemophilia and Thrombosis Center, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Universit degli Studi di Milano
Mark Skinner - President, Institute for Policy Advancement Ltd.

NURSES TRACK: UNMET AREAS OF EVIDENCE BASED NURSING IN BLEEDING DISORDER CARE

As the role of hemophilia nurses continues to expand globally, they are practicing at ever-more advanced levels, delivering totally nurse-led care. The sessions cover best evidence-based practices, and look at how the role of the nurse in delivering care will change dramatically over the coming years.

SPEAKERS

Kate Khair - Director of Research, Haemnet
Chris Guelcher - Pediatric Nurse Practitioner, Children's National Medical Center
Debra Pollard - Lead Nurse, Specialist Practice, Haemophilia, Katharine Dormandy Haemophilia & Thrombosis Centre
Kelly Tickle - Pediatric Nurse Practitioner, Childrens Healthcare of Atlanta
Mahmoud Abu-Riash - Senior Clinical Specialist, King Faisal Specialist Hospital and Research Centre

WFH EDUCATIONAL: IMPACT OF CHALLENGES OF BLEEDING DISORDERS IN WOMEN AND GIRLS

The session highlights the challenges women and girls experience in getting proper diagnosis, care, and treatment for their bleeding disorder. What are the global and personal impacts of having a bleeding disorder for women and girls? The session addresses key issues such as reproductive challenges, diagnostic dilemmas, and treatment options for heavy menstrual bleeding. The session also shares examples of what actions are being taken to improve the lives of women and girls worldwide with bleeding disorders. The session includes a presentation on the impact of the COVID-19 pandemic on women and girls with bleeding disorders.

SPEAKERS

Roshni Kulkarni - Professor Emerita of Pediatrics and Human Development, Director, Michigan State University
Rezan Abdul-Kadir - Consultant Gynaecologist, Royal Free London NHS Foundation Trust
Michelle Lavin - Clinical Research Fellow, Irish Centre for Vascular Biology at the Royal College of Surgeons in Ireland
Tahira Zafar - Chairperson, Medical Advisory Board, Pakistan Haemophila Patients Welfare Society
Robert Sidonio - Pediatric Hematologist/Oncologist, Emory University

WFH EDUCATIONAL: TREATMENTS FOR BLEEDING DISORDERS: CURRENT ENVIRONMENT AND PIPELINE PRODUCTS

There are novel products newly arrived on the market (longer half-life, non-factor products) that are very different from traditional clotting factor concentrates which pose new questions about safety and clinical use. Furthermore, gene therapies may revolutionize hemophilia care. Finally, these new technologies mean the global supply of all treatment products continues to grow, opening up the possibility for greater access to treatment in under-served areas of the world.

SPEAKERS

Radoslaw Kaczmarek - Postdoctoral Research Associate, Hirszfeld Institute of Immunology
Flora Peyvandi - Professor of Internal Medicine, Angelo Bianchi Bonomi hemophilia and Thrombosis Center, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Universit degli Studi di Milano
Dan Hart - Consultant Haematologist, The Royal London Hospital Haemophilia Centre
Johnny Mahlangu - Professor of Haematology, University of the Witwatersrand and NHLS

NURSES TRACK: EMERGING HEMOPHILIA NURSING SKILLS

The session covers best evidence-based practices and looks at how the role of the nurse in delivering care will change dramatically over the coming years.

SPEAKERS

Kate Khair - Director of Research, Haemnet
Amber Federizo - Medical Director, Hemostasis & Thrombosis Center of Nevada
Michelle Witkop - Head of Research, National Hemophilia Foundation
Regina Butler - Clinical Manager, Childrens Hospital of Philadelphia
Cathy Harrison - Advance Nurse Practitioner, Sheffield Haemostasis & Thrombosis Centre

WFH EDUCATIONAL: WFH GLOBAL INITIATIVE FOR BETTER CARE OF VWD

VWD is the most common bleeding disorder yet it is greatly undiagnosed. It is challenging to diagnose particularly or developing countries. The Committee shares practical ways to diagnose that would work in all contexts around the world and educate the community on management.

SPEAKERS

Margaret Ragni - Tenured Professor of Medicine and Clinical and Translational Science, Department of Medicine, Division of Hematology/ Oncology, University of Pittsburgh
Augusto Federici - Associate Professor of Hematology, University of Milan
Roshni Kulkarni - Professor Emerita of Pediatrics and Human Development, Director, Michigan State University
Rezan Abdul-Khadir - Consultant Gynaecologist, Royal Free London NHS Foundation Trust

You're invited to the 2020 HFNZ Adult Weekend!

If you're 25 or over, and you've been hanging out for some HFNZ education and social time, then we have some great news for you!

Coming up in Christchurch on 6-8 November 2020 is the first HFNZ national event since lock-down: The 2020 HFNZ Adult Weekend.

Living with a bleeding disorder, or living with a person with a bleeding disorder, is challenging. Adult Weekend is an opportunity for adults with bleeding disorders to openly discuss their experiences, challenges, and concerns about living and aging with a bleeding disorder. The focus of the weekend is to increase knowledge about bleeding disorders, upcoming trends and treatments, aging with a bleeding disorder, and the provision of health care in New Zealand, as well as learning about HFNZ and its activities.

Southern Outreach Worker, Ross, is working on the programme, and so far it's looking fantastic! We have an expert HFNZ panel lined up, a haematologist, a nurse, and a psychologist, all concentrating on the theme that 'life is a highway'. That means talking about the challenges you might encounter along the way, as well as the good things.

Along with the education, there'll be plenty of chances to enjoy some social time, as well as a couple of interesting outings.

To top it all off we're aiming to finish up with the HFNZ AGM on Sunday afternoon. This is a great opportunity to really engage with the running of your foundation.

The registration fee for the weekend, including flights and accommodation is $100 per person or $150 per couple. You can choose to pay via internet banking as soon as you like, or you will be invoiced closer to the date.

Please use your family name as a reference.

Account Name: Haemophilia Foundation of New Zealand

Account: 02 0828 0102656 000

To make any other arrangements please contact Leanne at head office: admin@haemophilia.org.nz

So, sign up today:
https://2020-hfnz-adult-weekend.lilregie.com/

The link will take you to the sign-up page, hosted by Lil Regie, where you'll be able to give us all your details, and sign up your other half too. Then all you have to do is sit back and wait for November.

We're looking forward to seeing you then!

Outreach and Member Details

In order to increase the reach of HFNZ communications, and improve member outcomes, Outreach have begun updating member details in the database. Over the coming weeks members will be contacted to add missing details. The most important details are email addresses and dates of birth.

Having a current email address for you and your whānau is important as we try to manage costs. Posting invitations and information to members is an expensive business, and where possible we would prefer to make contact electronically. If you have an email address, but you're not sure that we have it, please let your Outreach Worker know.

The other essential detail is date of birth. We need this so that we can be sure you're on the list for age-restricted events, like Adult Weekend and Women's Weekend. If we have no DOB for you, the database won't filter you in to age-based mailing lists. Again, if you're not sure whether we have your DOB, please let your OR Worker know.

Please find your OR contact details below.

As many of you already know, the National Council has decided not to seek a new Midland OR Worker until 2021. During this time, members in the Midland region will continue to be supported by either Northern OR Worker Amber Maihi or Central OR Worker Lynne Campbell.

Amber Maihi - Northern OR Worker

Lynne Campbell - Central OR Worker

If you live in the Waikato DHB catchment your OR contact is Amber Maihi at amber@haemophilia.org.nz or on 027 512 1114.

If you live in the Bay of Plenty or Lakes DHB catchments, then your OR contact is Lynne Campbell at lynne@haemophilia.org.nz or on 027 273 3443.

Please refer to the image below to figure out the DHB you're in, and which OR Worker currently supports you.

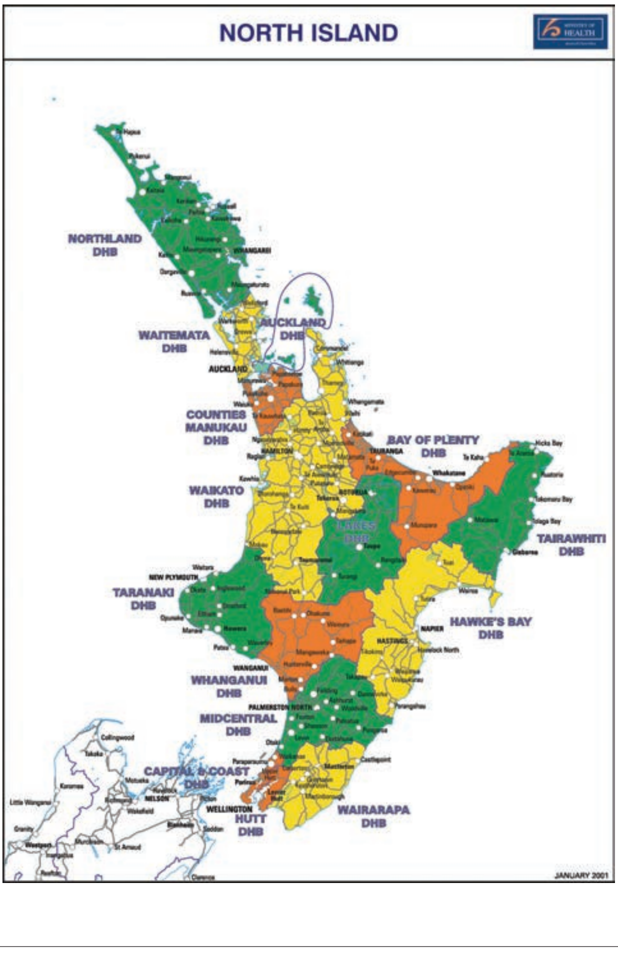
Since the Covid-19 lockdown, Outreach staff were advised not to undertake any travel. We are pleased to say that there is now the ability for OR Workers to travel to meet with HTCs and members. With reduced funding due to the Covid situation, OR Workers still need to manage their travel well. That means, for some people, it may still be more appropriate to connect with you via phone, text, email, or video. Please contact your OR Worker to organise the best way for you to connect with them:

Southern: Ross Paterson - ross@haemophilia.org.nz, 021 656 804

Ross Paterson - Southern OR Worker

Central: Lynne Campbell - lynne@haemophilia.org.nz, 027 273 3443

Northern: Amber Maihi - amber@haemophilia.org.nz, 027 512 1114



Looking after ourselves

BY ROSS PATERSON – SOUTHERN OUTREACH WORKER

Spectacular views from the top of the Port Hills

Hello Port Hills walkers. As we are about to get underway with our walking programme again, I have been reflecting on the lockdown and the aftermath and what it has meant to me in terms of my health.

The World Health Organisation defines six essential components of health. "Each of these components is somehow integrated and incorporate social, physical, spiritual, cognitive, emotional and cultural health." I am not going to attempt to dissect my performance in relation to each of these components of health but rather to look at one aspect, namely my physical health.

As many of you will no doubt be aware, living a well-balanced lifestyle that combines physical fitness, healthy nutrition, and adequate rest can manage, control, and even eliminate illness and disease. (Unfortunately, it does not eliminate bleeding disorders!) During lockdown I was fortunate to be able to exercise on a daily basis and enjoyed my regular morning walks, and the other exercise I fitted in (without breaking lockdown rules!) but as most of us are aware, and is noted above, our physical health is about more than just exercise.

"Studies have proven that maintaining physical health improves your mood and reduces anxiety and depression. People who exercise regularly were shown to have increased serotonin and norepinephrine levels, which are hormones naturally produced in our body to relieve depression. If you exercise regularly, it will also improve your skin, strengthen your bones, increase your energy levels and reduce your chances of developing chronic diseases. However, there is a lot more to it than hitting the gym five times a week. Often a person can have the biggest biceps and best abs in the world, but still be in poor physical health. There a lot of other things to factor, including a proper diet, nutrition, avoiding drugs and alcohol, and a healthy sleep routine."

In my case I maintained a healthy diet but on reflection my food consumption was greater than I needed. (In other words I was a bit piggy during lockdown and afterwards!) In addition, I indulged in some binge Netflix watching and so I wasn't always getting adequate rest, and I am aware that these two factors resulted in my feeling sluggish in the mornings. I was informed through the media and anecdotally that some people found themselves drinking more alcohol than usual and for some of us that maybe something to reflect on. Some people are practicing "dry July" and others are reducing their alcohol consumption to weekends only to get the balance they want in their lives.

Enough navel gazing, check out the revised walk schedule, and let's get walking in those hills!

Revised schedule for Port Hills walks 2020

After the Covid 19 hiccup, here is our amended schedule for the year:

Sunday 31st July: Victoria Park to the Sign of the Kiwi, via Harry Ell Walkway.

Starts from just above the Sign of the Takahe at Elizabeth Park Car park which is opposite Elizabeth Park and the dog exercise paddocks immediately below Victoria Park, sidles gently below Victoria Park and goes up to the Sign of the Kiwi through bush and pine trees up to the Sign of the Kiwi. 1.5 to 2 hrs return.

Sunday 30th August: Coopers Knob to Cass Peak and Sign of the Bellbird

Sweeping views on the first section of the Crater Rim walkway. From Ahuriri Bush carpark, wander along the ridge track to Coopers Knob, through bush, climbing out along an impressive line of bluffs to the Sign of the Bellbird carpark. 2 hrs return approx

Sunday 27th September: Godley Head Circuit

Our next walk starts from the Taylors Mistake Carpark (Car park is at the end of the road in Taylor's Mistake close to the Taylor's Mistake beach) and takes us out to Godley Head on the Godley Head Circuit. This is a longer walk (3 hrs approx), than our previous two but is not as steep.

Sunday 25th October: Ella's – Totara Log – Bivvy Track Circuit

From the carpark (opposite Kennedys Bush Road) follow the Crater Rim Walkway under Mt Ada, along Ella's track. Then take the Totara Log Track where it intersects with the Bivvy Track. 1.5 to 2 hrs return.

Sunday 29th November: Captain Thomas & Scarborough Bluffs Circuit

Starting from Sumner, the Captain Thomas track winds up alongside Evans Pass Road to Rapanui Reserve. The Scarborough bluffs track then sidles down the other side of the valley, crosses Evans Pass Road and descends via the Waterfall Track into Sumnervale Park. 2 hrs return

More detail for trips will come out monthly and this information will be repeated in the next Bloodline. A useful resource for these walks is Mark Pickering's The Port Hills. For about $10 you will find detailed information about these walks.

Looking over the Canterbury Plains

Regions and Groups

HFNZ's Regional and Group committees enable all our members to participate in the running of the Foundation, and to connect with and support one another. Due to the Covid situation, events have been limited so far this year. Instead, here's some insight into how things went for our regional reps during lockdown.

CENTRAL UPDATE

BY BLAIR WIGHTMAN

The COVID restrictions impacted a few of our events but we're now well advanced with getting these back on track. Our Regional Camp is all set for 28 - 30 August at El Rancho in Waikanae.

We are holding our AGM on Saturday 28 August at Camp and all members are welcome to attend the educational sessions, AGM and lunch from 9am to 1pm. You should have received your invite and registration for Camp by now. If you haven't, please let us know. Also, let us know if you are local and would like to attend the Saturday morning sessions only.

This year our central region Chairperson (me, Blair Wightman) and National Council Delegate (Stephanie Coulman) are both standing down and so we're looking for members to step up and take on these roles.

The central committee's role is mostly focused on organising the 3-4 events each year we run in the region and we're keen for people across the region to join. The commitment is around 1-2 hours per month. The National Council Delegate role is slightly more time consuming, but is an opportunity to be involved in the Foundation's strategy and governance processes.

We've also booked in the Wellington screening of the Bombardier Blood movie and are now holding this on 28 November as our end of year event. Invites will be sent out closer to the time. The Men's fishing trip is also back on the agenda and we'll confirm dates shortly.

My reflections on the lockdown period…

AN ACROSTIC ODE TO LOCKDOWN

Lots of bonding with the family
One o'clock updates from Dr Bloomfield.
Cooking, cooking and more cooking
Kilos kept off with plenty of exercise
Deep respect for the work of our teachers
Oh, where can I buy some yeast?
Weekday juggling of work and school
Not another Zoom meeting!

NORTHERN REPORT

BY GREG JAMIESON

Lockdown for our family was a big scary unknown. We thought we were going to lose $7k worth of travel we had booked to depart to the Gold Coast in May, we weren't sure how we were going to manage working from home and how the kids were going to cope, and we were also concerned about our parents and how they were going to cope.

However, it's like that poem the Haemo people give you when you first find out that your kid has haemophilia, about going to Holland. Lockdown for us personally was good, and many great things came from it including:

- We had awesome quality family time with walks to the local beach, board games, movies and family projects - who knew an 8 year-old could paint a fence?
- Working from home for me was hard for the first few days but after that was great. I got 1.5 hours a day back in to my personal life because of not having to commute.
- I was more productive working from home as there are no distractions like at the office so I got my work done quicker
- I got on to projects around the house that I have put off for years
- I had time to get back into running and improve my health
- I got 95% of our money back for our holiday
- My parents never got sick

So all up for us the lockdown was actually a blessing and I have locked down some of the wins in to my life going forward including working from home 3 days out of 5, keeping up the morning runs and the almost nightly family game of Rumeo.

Covid has slowed things down for Northern too. We had to cancel our movie event planned just as we were heading in to lock down. Fortunately, we were able to get a full refund.

For the safety of our region, we haven't planned any events in the short-term, as we wanted to make sure the virus was under control. We will be looking at options for later in the year to get our people together.

On behalf of the Northern committee, I hope you are all safe and well.

MIDLAND REPORT

BY TINEKE MAOATE

Life in the Maoate household during the Covid lockdown.

We were asked how we survived the lockdown at the Maoate household. Well, with a family of nine, and a few foster children here and there, it was a very busy lockdown! Both John and I had to work throughout lockdown, as John is a police officer and I work with FENZ and Oranga Tamariki, which were all classed as essential services. It was a very scary time for us as one of our sons has a serious respiratory condition, which is life threatening. With us having to be out in the public, we ran a very high risk of becoming infected.

However, this was nothing compared to home schooling our children. I fully believe that all parents of school age children have a lot more respect for their children's teachers now, and understand why there are school holidays. To give the teachers a break from our children.

But on the bright side less accidents as the board games came out and the battle of Buzz* were played. Not to brag, but I was the reigning champion of the game 70s, 80s, and 90s music quiz on Buzz.

Overall, we made it through the lockdown with all bodies accounted for and all foster children in great care. The bonus was we didn't have a divorce. I class that as a successful lockdown!

**Buzz is a PlayStation 2 game for those who are too young to know or too old to remember.*

PIRITOTO UPDATE

BY ROSALIE REIRI

Tēnā rā koutou katoa

I hope everyone is well post-Covid, and that your return to business-as-usual is anything but usual. The key Piritoto updates are that Tuatahi Pene and Laura Watson have blessed the whānau with another mokopuna, Maianahera, and Hautapu Baker and Kalei Delamere-Ririnui had a baby girl Maireikura. Nau mai ki te ao, nau mai ki te whānau o Piritoto.

The Piritoto plans pencilled in for 2020 have been placed on pause, so instead of sharing Piritoto updates, I will share an insight into our lockdown experience. Lockdown reminded me of growing up in a small rural town where the streets were quiet, time was not a factor, and home-cooked meals were a treat. The importance of whānau, having moko at home, gave peace-of-mind, knowing our whānau were safe. Getting back to basics was a wonderful lesson to return to. My Covid highlight, or what kept me going, was the exercise regime of getting out of the house and going for a walk or doing an online gym class. What were your Covid highlights?

SOUTHERN REPORT

BY SUSAN INWOOD

Welcome to July 2020!

Phil has asked that we submit a little bit about how we coped with the lockdown this year.

Surreal is a good word here I think.

Although I live in a bus, I am lucky enough to live on the same property as my daughter, son-in-law, and three of my grandchildren-aged 5½, 4 and 2 and I was in their "bubble" thankfully. The first week and a half was trying for the children, as they weren't allowed to go off the property. However, with the internet as inspiration, my daughter found quite a few activities for them. Colouring pages, scavenger hunts, exercises in the form of children's yoga to name a few. I was able to take them "kayaking" in their swimming pool every day as well, which they enjoyed.

I work at the Community Laboratory, so we were considered essential workers. Very eerie on the roads with little traffic and then working different shifts and with the social distancing made for a very odd feeling. The break room was so quiet; nobody knew how to act…

It feels like the year has accelerated and we are left wondering what happened!

I hope this issue finds everyone well and coping being back to whatever normal we can find.

YOUTH

BY COURTNEY STEVENS

Lockdown was certainly an interesting experience, I don't know about you guys, but I am happy to never work from home again. Like some others, I opted to head back home to Dunedin to hang with the fam during lockdown, having Mum's dog for entertainment was a definite bonus!

The move down to levels 3, 2 and 1 subsequently were a welcome change. I didn't realise how much I actually enjoyed going into the office until I had to stay away for 8 weeks! I know not everyone was lucky enough to be able to keep working during lockdown so I am grateful that working from home was possible for me. Sharing an office with my family made phone calls difficult at times given the volume levels but all-in-all it went pretty well.

Unfortunately, we've had to re-evaluate our twinning given the current travel restrictions. We recently had a Zoom meeting with Nepal, coordinating the time difference proving harder than originally anticipated! However, we've come up with some solid options, and are in discussions with WFH about a way forward.

I hope everyone survived lockdown okay, I'm looking forward to catching up with everyone again soon at upcoming events!

Youth twinning Zoom meeting with representatives from Nepal

Gene Therapy Shows Promise For Hemophilia, But Could Be Most Expensive U.S. Drug Ever

BY ROB STEIN

Biomarin Pharmaceutical, a California company that makes what could become the first gene therapy for hemophilia, says its drug's price tag might be $3 million per patient.

Jack Grehan, who was born with hemophilia, used to inject himself every couple of days with a protein he needs for his blood to clot. But not anymore.

"It's been absolutely brilliant and life-changing for me," says Grehan, 26, of Billinge in North West England. He received an experimental gene therapy in 2017 that, at least for now, has eliminated his need for regular injections. "I can just go about my day and not have to worry."

Based on experiences like Grehan's, the company that developed the therapy is seeking approval in Europe and the United States to start selling the first gene therapy for hemophilia. That's generating excitement among patients, patient advocates and doctors.

"Not to have to worry about hemophilia any longer — I think it's essentially transformational for many patients," says Dr. John Pasi of the Royal London Hospital and the London School of Medicine and Dentistry. Pasi led the recently published study Grehan took part in.

Others are more cautious.

"This is really exciting, but also raises a lot of questions," says Meg Bradbury, director of research at the Hemophilia Federation of America, a patient advocacy group.

One of the biggest questions is the possible cost. BioMarin Pharmaceutical Inc. of San Rafael, Calif., the company that developed the gene therapy, says the treatment could cost as much as $3 million per patient, which would make it the most expensive drug ever approved.

"It's just outrageous," says Peter Bach, who studies drug prices at Memorial Sloan Kettering Cancer Center in New York.

Company officials defend the possible price, however. It currently costs hundreds of thousands of dollars a year to treat each hemophilia patient. The gene therapy would, researchers hope, be a one-time treatment that lasts a lifetime.

"The context is this gigantically expensive disease to treat," says Jeff Ajer, BioMarin's executive vice president and chief commercial officer. "It's likely that our gene therapy would save a lot of money — millions, perhaps many millions."

Hemophilia is a relatively rare condition. Hemophilia A, the most common form of the disease, occurs in 1 of about every 5,000 boys. (Though girls can be born with hemophilia, too, that's much rarer.) People born with the condition are missing a crucial protein that their blood needs to clot. So doing things as simple as walking can cause dangerous bleeding in their joints that eventually can be crippling.

"It was quite difficult, because I was always getting these bleeds in the ankles," Grehan says. "So walking around was becoming more and more troublesome."

Grehan has a severe form of hemophilia A, which causes a deficiency in a clotting protein called factor VIII.

"It's the microbleeds that just sort of wear your down — not even physically but mentally," Grehan says.

And Grehan knew that propensity to bleed could cause even more serious, possibly fatal, complications if the hemorrhage every happened in his brain or other parts of his body.

"Internally, there could have been a lot worse situations," Grehan says. "I consider myself quite lucky in that respect."

Before anything like that happened to Grehan, he learned that doctors were testing the gene therapy.

"When I first heard about the trial I thought it was unbelievable that we were in this situation — that this even existed," Grehan says.

So he volunteered three years ago to let doctors infuse trillions of neutralized viruses that had been genetically engineered to carry the healthy gene he needed into his liver.

Within a couple of weeks, Grehan could stop injecting himself with the clotting protein that he had previously needed.

In fact, the treatment dramatically cut bleeding in all 13 of the patients who got the effective dose of gene therapy determined by the study Grehan was in.

"I think it's amazing data actually," Pasi says. "It's been the Holy Grail for years to be able to treat hemophilia with a gene therapy treatment. And maybe we're beginning to see that that wasn't a pipe dream — that this is a realistic option."

It's the latest promising development for gene therapy, which has finally started producing effective treatments for a variety of diseases after decades of setbacks.

Several other experimental forms of gene therapy are also showing promise for hemophilia, including another type of the condition, known as hemophilia B.

So far, nearly 150 patients have been treated with BioMarin's gene therapy as part of a larger study, and the results continue to be encouraging, according to the company. Some patients having been followed for as long as four years.

"For a good fraction of these people, they don't have to even think about having hemophilia anymore," says Henry Fuchs, president of research and development at BioMarin.

The Food and Drug Administration has designated the treatment a "breakthrough" therapy and accepted the company's application to give the gene therapy priority status for evaluation, representatives of BioMarin say. That makes it the first gene therapy for hemophilia the agency has agreed to consider.

According to the company, the FDA has signaled it will make its decision by Aug. 21 about whether to approve the treatment for sale.

Longer studies will be need to determine if the treatment is, in fact, a one-time, therapy for lifelong effect, experts say.

"It seems to be working very well, but we are only at three years," says Dr. W. Keith Hoots, director of the division of blood diseases and resources at the National Heart, Lung and Blood Institute. "We need to know for sure whether it will extend for their entire life. And only time will tell for that."

Nevertheless, Bach agrees the treatment appears very promising. Still, he questions the price tag, which would be just the latest in what appears to be an ongoing rise in the cost of the new wave of genetic therapies.

"The clinical breakthrough is prodigious. We should be thrilled by it," Bach says.

"But the greatest innovation by the pharmaceutical industry is not the biologic breakthroughs they're making," he says. "It's their ability to extract money from society that we could put into other things — like better benefits in Medicare, lower out-of-pocket costs for poor people, dental coverage and things like that."

The prices of the drugs already used to treat hemophilia are inflated, Bach argues.

Bradbury, from the Hemophilia Federation of America, agrees cost is a concern.

"We need to make sure all those who are eligible would have access to it," Bradbury says.

Ajer says the company has already been negotiating with insurance companies and government programs to cover the costs.

"Our work is not done here, but my expectation is that most of the patients who need access to therapy would be able to get it, in not a terribly long time, through their insurance system," Ajer says.

As someone who has had to deal with hemophilia all his life, Grehan thinks the price is reasonable.

"I think $3 million for this is very cheap — because it is life-changing," Grehan says. "And if you're going to spend hundreds of thousands of dollars a year over a lifetime, that seems worth it to me."

Source: https://www.npr.org/sections/health-shots/2020/07/20/800556057/gene-therapy-shows-promise-for-hemophilia-but-could-be-most-expensive-u-s-drug-e

#ISTH2020 – FLT180a Gene Therapy Shows Promise for Hemophilia B Patients in Phase 1/2 Trial

BY JOANA CARVALHO, PHD

A single dose of the investigational gene therapy FLT180a can lead to clinically meaningful, sustained increases in the activity of factor IX (FIX), effectively preventing bleeds and the need for replacement therapies in people with severe hemophilia B, a Phase 1/2 clinical trial shows.

These results support the start of a pivotal Phase 3 trial of FLT180a, according to the researchers.

Trial findings were presented by Pratima Chowdary, MD, chief investigator of the trial, in a presentation titled "A Novel Adeno Associated Virus (AAV) Gene Therapy (FLT180a) Achieves Normal FIX Activity Levels in Severe Hemophilia B (HB) Patients (B-AMAZE Study)," at the 2020 Congress of the International Society on Thrombosis and Haemostasis.

FLT180a is an experimental gene therapy for hemophilia B being developed by Freeline. It uses the company's adeno-associated virus (AAV) protein shell, called AAVS3, to deliver a functional version of F9 — the gene that provides instructions to make FIX — to liver cells. FIX is the blood-clotting protein missing in people with hemophilia B.

The safety and effectiveness of four single doses of FLT180a are being investigated in adult men with moderately severe to severe hemophilia B participating in a Phase 1/2 trial (NCT03369444) called B-AMAZE. The study, which will enroll an estimated 24 patients, is still recruiting at several sites in the U.K., U.S., and Italy.

B-AMAZE has an adaptive design that allows investigators to either increase or decrease the dose at which FLT180a is administered to rapidly identify that which most effectively allows patients to maintain their FIX activity levels within a normal range (50–150% of what would be considered normal).

In addition to determining the best dose to restore blood clotting and lessen or eliminate the need for additional prophylactic (preventive) treatments, the trial is also aimed at establishing a strategy to prevent and control transaminitis (high levels of liver enzymes), one of the most common side effects of AAV gene transfer that may lower the production of FIX.

"Transaminitis is the single biggest risk factor for loss of the effect of gene therapy, because once you have transaminitis, you lose expression of the protein, and once it is lost, it is practically irreversible," Chowdary said in an interview after her presentation.

"I think [B-AMAZE is] one of the first studies that has implemented upfront immunosuppression [to manage and prevent transaminitis] for all patients," she added.

Previous data from the first eight men treated in B-AMAZE showed that FLT180a was able to increase and maintain FIX activity within a normal range, when given at a dose of 9.75×1011 vector genomes per kilogram (vg/kg).

New findings presented at the meeting included data from 10 men with severe hemophilia B who received one of four doses of FLT180a: 4.5×1011 vg/kg, 7.5×1011 vg/kg, 9.75×1011 vg/kg, or 1.5×1012 vg/kg.

The first two patients who received the lowest dose of FLT180a (4.5×1011 vg/kg) saw their FIX activity levels rise and stabilize just below the normal range (approximately 40%) for more than two years. None of the patients developed transaminitis. The observed FIX levels were in line with mild hemophilia B.

A slightly higher dose (7.5×1011 vg/kg) led to a modest increase in the levels of FIX, which was enough for one of the two patients dosed to reach the normal range. Both had transaminitis with different severity that was managed with methylprednisolone and tacrolimus.

For the four men who received a lower 9.75×1011 vg/kg dose, FIX activity levels normalized three weeks after treatment. In the two men who have been followed for six months, FIX activity remains within a normal range.

In this group, a preventive combination therapy of corticosteroids with the immunosuppressant tacrolimus seemed to be effective at preventing transaminitis during the high-risk phase, which is 4–16 weeks following treatment with FLT180a.

Of the two patients who received the highest dose of the therapy (1.5×1012 vg/kg), one saw FIX activity rise beyond normal levels and had to be started on prophylactic anti-coagulation treatment with apixaban four weeks after receiving FLT180a. At week 33, the patient stopped treatment with apixaban after experiencing a possible bleeding episode in his elbow.

However, a few days after stopping treatment with apixaban, he had an episode of thrombosis and was restarted on anti-coagulants.

None of the participants developed neutralizing antibodies against FIX or experienced infusion reactions.

According to the investigators, the findings indicate that a "dose between 7.5 to 9.75×1011 vg/kg can potentially create sustained, normal FIX activity levels in patients with severe [hemophilia B]."

"Over a period of two years, we also learned what is the right combination of immunosuppressible immunomanagement strategy that will allow us to prevent and manage the transaminitis," Chowdary said. "We believe strongly that prophylactic immunosuppression would be the right thing."

Source: https://hemophilianewstoday.com/2020/07/17/isth2020-flt180a-leads-to-sustained-increases-in-fix-activity-phase-1-2-trial/

Out to the beach at Inhibitors Workshop 2020

THE YEAR AHEAD

August 28–30, 2020

- Central Camp
  El Rancho, Waikanae

November 6–8, 2020

- Adult Weekend & HFNZ AGM
  Christchurch

April 29–May 2, 2021

- Youth Camp
  Kaiapoi

Late 2021

- Women's Weekend
  Date and venue to be determined

Early 2022

- National Family Camp
  Date and venue to be determined

Visit www.haemophilia.org.nz for more information on bleeding disorders, HFNZ News, and past issues of Bloodline

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