

WEBINAR

# STEPPING UP AND NOT STEPPING OUT

A NURSING AND PSYCHOSOCIAL  
PERSPECTIVE TO COVID-19



Glenn Pierce, MD, PhD

Kate Khair, PhD, RN

Marlène Beijlevelt, MSc, RN

Richa Mohan, MA, M.Phil

Edward Kuebler, MSW, LLC

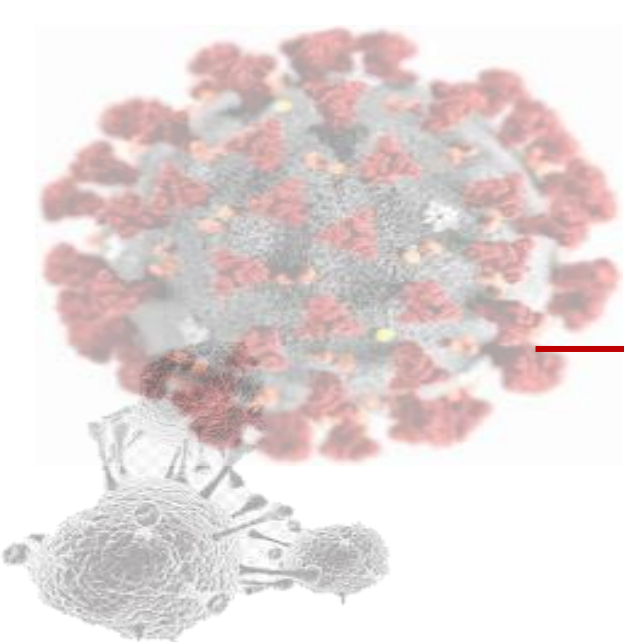
Flora Peyvandi, MD, PhD

Monday, 4 May 2020



**WFH**

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# SPEAKERS & PANELISTS

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Glenn Pierce,  
MD, PhD



Edward Kuebler,  
MSW, LLC



Richa Mohan,  
MA. M.Phil.



Kate Khair,  
PhD, RN



Marlène Beijleveld,  
MSc, RN



Flora Peyvandi,  
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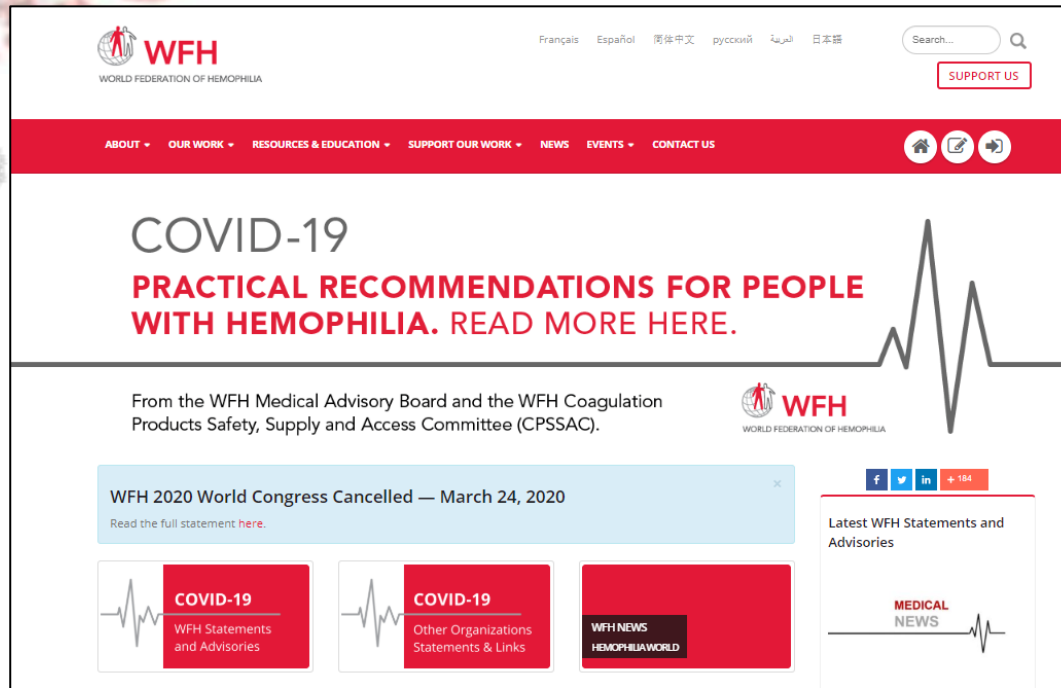
# AGENDA

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- **Managing Haemophilia and COVID-19 in Daily Life**  
*Marlène Beijlevelt, MSc, RN, Kate Khair, PhD, RN*
- **Dealing with Anxiety and Fear in COVID-19 Pandemic World**  
*Richa Mohan, MA, M.Phil.*
- **Isolation: Being Alone but Not by Yourself: Navigating Through Feelings of Isolation and Social Distancing**  
*Edward Kuebler, MSW, LLC*
- **Questions and Answers Period**  
*Chair, speakers and Flora Peyvandi, MD, PhD*



# WFH COVID-19 STATEMENTS



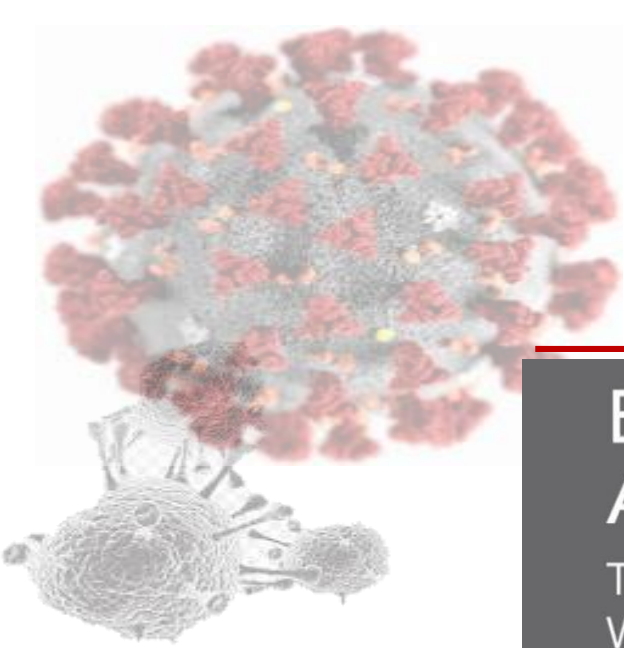
- Practical recommendations
- Specific risks of COVID-19
- Humanitarian aid news
- Company statements

## Specific Risks of COVID-19 to the Bleeding Disorders Community

World Federation of Hemophilia - April 2, 2020  
Also available in: **Español, Français**

<https://www.wfh.org/en/home>





# ASKING A QUESTION

## BLEEDING DISORDERS AND COVID-19

THE FACTS AND RISKS TO PERSONS  
WITH BLEEDING DISORDERS



Glenn Pierce, MD, PhD  
Flora Peyvandi, MD  
Magdy El Ekiaby, MD  
Cedric Hermans, MD  
Radoslaw Kaczmarek, PhD

Thursday, 9 April 2020



Audio Settings ^



Leave Meeting

If you have not sent your question to [research@wfh.org](mailto:research@wfh.org), you can ask a question in the Question & Answers section.

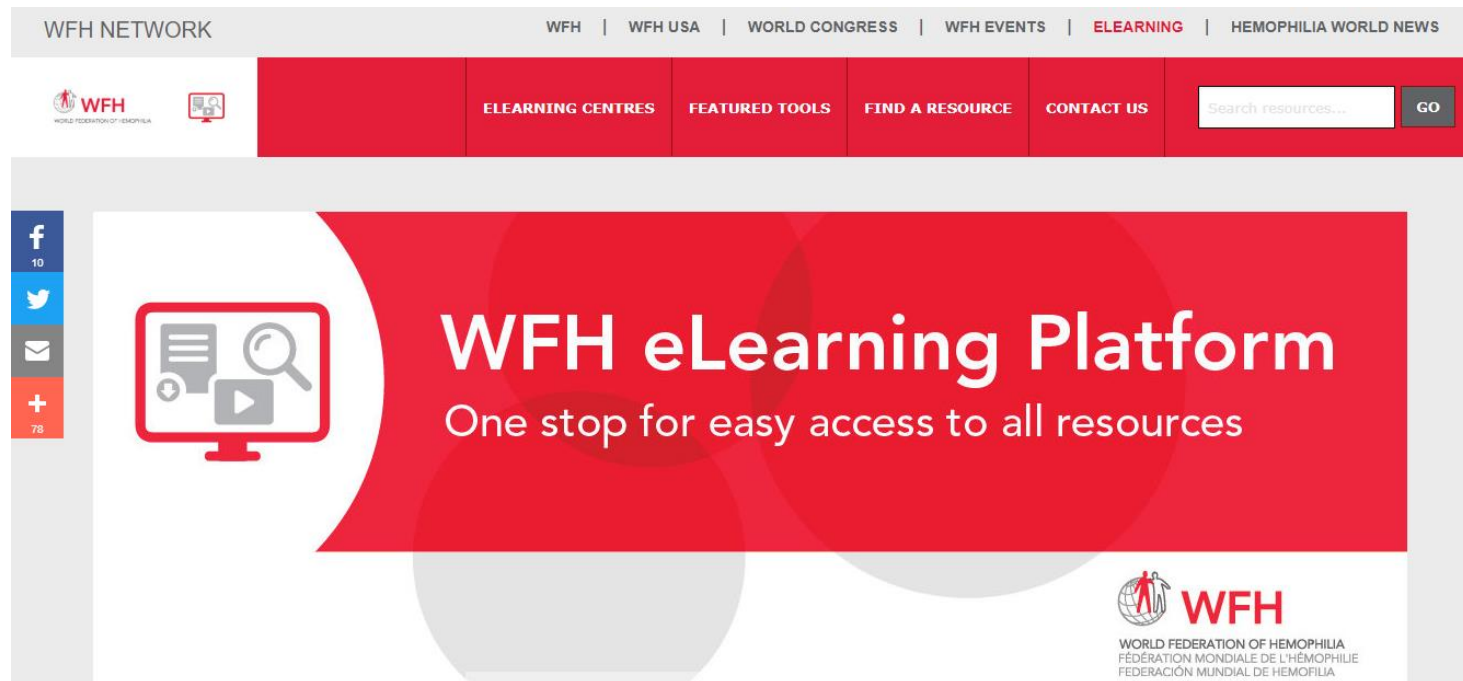
We will address as many questions as time allows.



# WEBINAR RECORDING

The recording of the webinar will be available on the WFH eLearning Platform on Tuesday, May 5<sup>th</sup>, 2020

<https://elearning.wfh.org/>



WFH NETWORK

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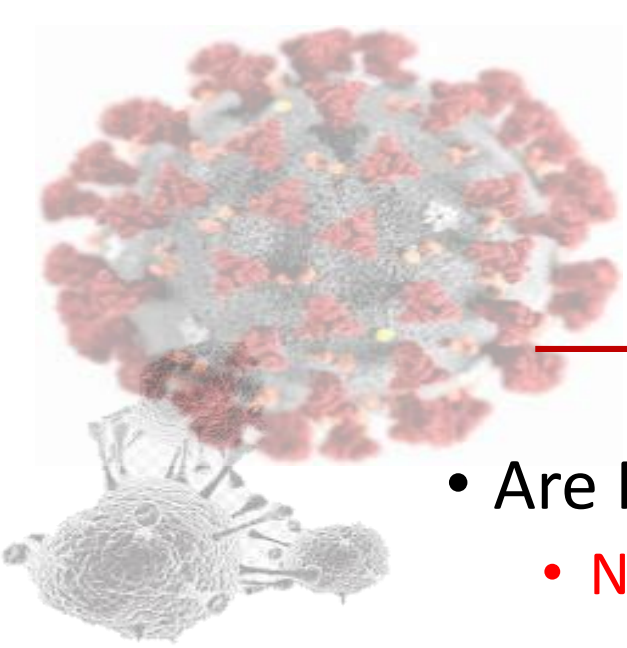
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WFH eLearning Platform  
One stop for easy access to all resources

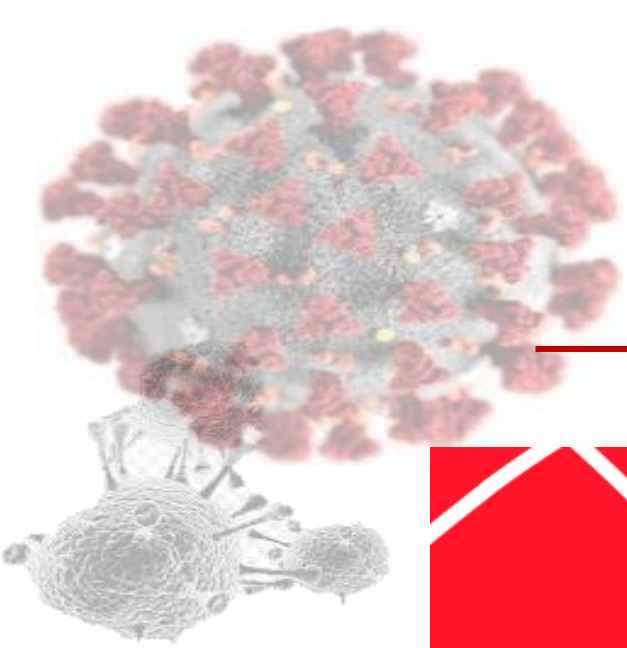
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# COVID-19 & Bleeding Disorders

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- Are PWH at increased risk of having COVID-19?
  - No. Risk factors for severity of disease
- Can COVID-19 be transmitted through plasma products?
  - Thought to be highly unlikely, being closely monitored
- Does COVID-19 treatment protocol require special care for people with bleeding disorders?
  - Yes. Management of coagulation deficiency is complex during severe COVID-19...



# WFH VIRTUAL SUMMIT

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**COVID-19 session on  
Friday, June 19, 9:00-10:00 EDT**



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# MANAGING HAEMOPHILIA AND COVID IN DAILY LIFE

**Kate Khair, PhD, RN**  
**Haemnet, London + Chair WFH Nurses Committee**

**Marlène Beijlevelt, MSc, RN**  
**UMC, Amsterdam + WFH Nurses Committee**



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# Where is my haemophilia team?

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- How to contact my centre
- How to manage my (my child's) bleeding disorder



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# How to keep in touch with my centre

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## ➤ Digital vs Face to Face reviews

### ➤ Your haemophilia team are still around



- May not be in Haemophilia centre
- Working from other areas of hospital or home

### ➤ Expertise is still there

- Might get 'virtual' assessment





# What do I do about bleeding?

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- Bleeds in you or your children
  - Your haemophilia team are still around
    - You are able to come for treatment
      - Might be somewhere else in hospital than the centre
      - Might be organized at a different hospital
    - Alternative for clotting administration eg DDAVP and/or Tranexamic acid
    - Extra precautions will be taken
      - NO 'drop in clinics' – only come at time when you are told to come
    - If you are admitted
      - We will screen you for COVID Infection
      - Max 1 visitor in hospital





# Accessing my centre and treatment

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How to contact my centre

- How to manage my (my child's) bleeding disorder
- What about surgery



# Surgery in COVID-19 time

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- Surgery

- Your haemophilia team are still around
  - Planned surgery will be postponed till after pandemic
    - Treatment plan is available
  - Acute surgery are always performed
  - Hospital admission according treatment plan
  - Extra precautions
    - Detect or exclude COVID Infection
    - Max 1 visitor in hospital
  - Follow up may be different to 'usual'



# Accessing my centre and treatment

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How to contact my centre

- How to manage my (my child's) bleeding disorder
- What about surgery?
- How to manage stocks



**EHC\_Haemophilia** @EHC\_Haemophilia · Apr 16

During the #COVID19 pandemic, it is important to stay #HealthyAtHome 🏠. This is why EHC and @EAHADnews have issued a joint statement calling for national governments to implement home delivery of treatment so that patients avoid frequent hospital visits. 🙌

# BREAKING NEWS

EHC-EAHAD Joint Statement on the Delivery of Home Treatment during COVID-19 Pandemic | EHC -...

🔗 ehc.eu



Brussels, 16 April 2020

*The European Haemophilia Consortium (EHC) and the European Association for Haemophilia and Allied Bleeding Disorders (EAHAD) have published today a joint statement on home delivery of treatment products and the management of the supply chain during the COVID-19 pandemic.*

The European Haemophilia Consortium (EHC) and the European Association for Haemophilia and Allied Disorders (EAHAD) are committed to the representation and support of the rare bleeding disorders community, the improvement of patients' lives, and the further development of scientific and medical research.

With COVID-19 deeply affecting Europe and its citizens, EHC and EAHAD consider essential that both patients and healthcare professionals remain well-informed during these uncertain times. The advancement and dissemination of knowledge can be our best weapon in the fight against this once-in-a-lifetime disaster. Therefore, EHC and EAHAD are adopting this joint statement on home delivery of treatment products, and supply chain management, during the COVID-19 pandemic.

Patients with rare bleeding disorders (RBD) require frequent injections of treatment products like clotting factor concentrates and/or other therapies. Many RBD patients are vulnerable populations (e.g. immune-compromised, etc.).

In ordinary times RBD patients would frequently visit their hospitals or pharmacies to collect their therapies. In COVID-19 times they should stay at home for safety reasons as per national guidelines.

In many – but not all – countries, home delivery of treatment products and home self-treatment by patients is a well-established standard, as per the European Principles of Haemophilia Care<sup>[1]</sup>.

Under these circumstances, EHC and EAHAD urgently call on all governments to implement this Principle nationally.

The delivery of treatment products can be organised by treatment centres (hospitals) or delivery companies. Deliveries should ensure an adequate supply of treatment products to achieve safe patient care, continuity of treatment, and avoidance of death or severe complications requiring healthcare services.

Additionally, now more than ever, it is prudent to be prepared for potential interruptions in treatment product supply chains; therefore, the EHC and EAHAD jointly recommend implementation of the Council of Europe's Haemophilia Principles 1<sup>[2]</sup> and 16<sup>[3]</sup> enabling patient representatives and clinicians to partner within their national systems on supply chain monitoring and management.

The EHC and EAHAD fully respect that each country's healthcare system is organised differently. However, now more than ever, we must act in unity and share best practice to protect the lives of patients, national populations and support national healthcare systems.





# Accessing treatment

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How to contact my centre

- How to manage my (my child's) bleeding disorder
- What about surgery?
- How to manage stocks
- How can I manage pain?



# Pain management

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- Be aware that some drugs MIGHT impact on COVID 19 outcomes
- Avoid non-steroidal anti-inflammatory drugs
  - Discuss drug therapy use with your hemophilia team
- Use alternatives:
  - Analgesia
  - PRICE



# Managing normality in my life today

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- What exercise can we do?
  - Obey rules in your area about going outside – think about social distancing
  - Use social media sites for exercise advice – your physiotherapist will help you for hemophilia specific advice
- How to manage my family if I am sick?
  - Ask for help
  - Think about who might help you today, who you wouldn't normally ask
- Careful with Social Media
  - Limit your access
  - Don't watch/listen to everything - Trust your instincts – if it sounds too good to be true it probably is (and vice versa)
- How should I plan to get back to normal?
  - Take it one day at a time
  - Celebrate the good things



# **DEALING WITH ANXIETY AND FEAR IN COVID 19 PANDEMIC WORLD**

## **ISOLATION: BEING ALONE BUT NOT BY YOURSELF: NAVIGATING THROUGH FEELINGS OF ISOLATION AND SOCIAL DISTANCING**

**Richa Mohan, Clinical Psychologist  
Empowering Minds, India**

**Edward Kuebler, MSW, LLC  
EKuebler Consulting, USA**



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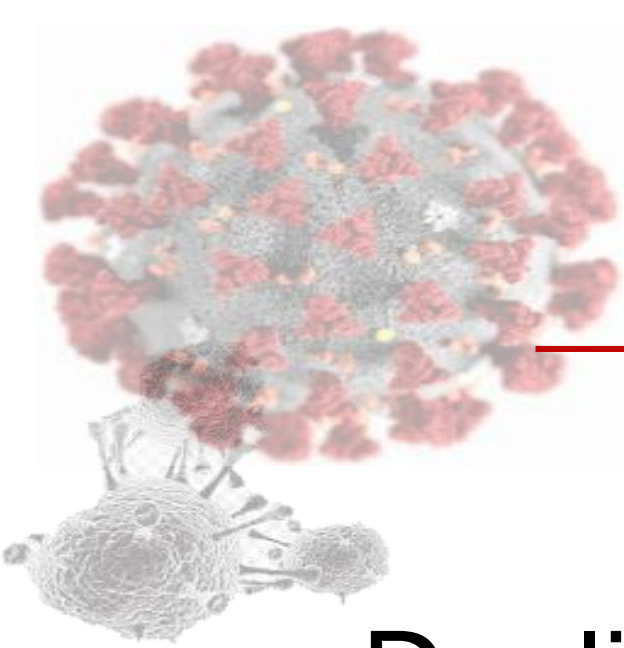




# Psychosocial issues our bleeding disorder community is facing

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- **Dealing with Anxiety and Fear during COVID 19 Pandemic World**
  - Stressors of Increased *Anxiety*
  - Increased *Fear*
  - Domains of **Triggers**
- **Isolation: Being Alone but Not by Yourself:** Navigating Through Feelings of Isolation and Social Distancing
  - Define Isolation
  - Isolation VS Social Distancing
  - Managing our feelings stimulated by fear and hopelessness
  - Defining a New Normal – For now and going forward



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# Dealing with Anxiety and Fear During COVID 19 Pandemic WORLD

Richa Mohan, Clinical Psychologist

Empowering Minds, India

4-05-2020

# COVID 19



PANIC

RUMOURS

ANXIETY

FEAR

DISTRUST

UNCERTAINTY

CONFUSION

IGNORANCE



# Normal fear response

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**DANGER**



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# Anxiety

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- ANXIETY is a very similar feeling which leads to arousal in the brain and at the same time in the body, different from fear in a specific way.
- Anxiety has nothing to do with a harm, but a overreaction to the consequences of an event and in this case COVID 19 Pandemic rather than the event itself.



# Domains of triggers

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- PUBLIC – Disapproval, Isolation, defeat
- Private – Abandonment, Discomfort, Disability/Illness, Death
- Based on Beck, Amery & Greenberg, 1985





## UNHEALTHY EMOTIONS

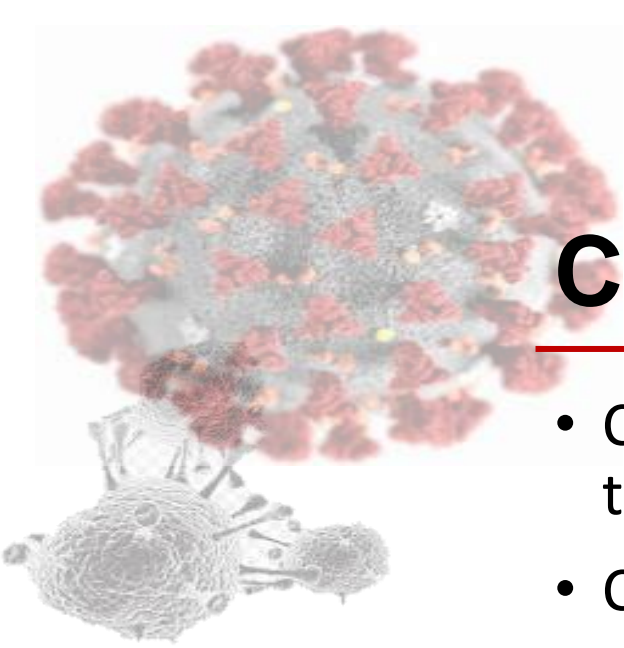
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- Depressed
- Unhealthy anger
- Anxiety
- Guilt
- Shame
- Hurt
- Hopeless
- Unhealthy Jealousy
- Unhealthy envy

## HEALTHY EMOTIONS

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- Sad but not depressed
- Healthy anger
- Concerned and not anxious
- Responsible and not guilty
- Disappointed with self but not ashamed
- Disappointed at others, but not hurt
- Realistically optimistic
- Healthy jealousy
- Healthy envy



# Concern

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- CONCERN can replace Fear and anxiety when there is no immediate threat
- Concern – is a healthy and negative emotion whereas anxiety is unhealthy and dysfunctional emotion.
- Concern can replace fear when there is no immediate threat, and they can limit their hypervigilance time when there are high risk for instance they are going out to the hospitals, or infusions, buy groceries, receiving couriers of AHF etc



## PRODUCTIVE WORRY

Focused on immediate realistic problems

Feels in control

Willingness to experiment with solutions and coping strategies

Willingness to put up with risk and uncertainty

High level of efficacy in coping

Lower anxiety

Focus on preventing or reducing harm

Focus on problem solving and building resources

Lesser physiological disturbance

## UNPRODUCTIVE WORRY

Focused on distant abstract problems

Feels out of control

Unwillingness to try any coping that has no guarantee, there is an absolute demand for certainty.

Unwillingness to put up with any risk and uncertainty

Feels helpless and unable to cope

Higher anxiety

Focus on a chain of consequences

Rumination

Higher physiological arousal and disturbance



# Effective ways of dealing with the COVID-19 situation

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- Get realistic estimation of your personal coping resources.
- Organise immediate surroundings example organising your works station at home, charger, reading books, cupboards, drawers etc this will induce **a sense of accomplishment.**
- Include activities that can give immediate results that one looks forward too, for instance gardening, learning a new activity, increasing proficiency in a language, **this gives a sense of control.**
- Talk to your friends and relatives over phone, with whom you didn't got the time to speak for quite a period of time, **this gives sense of belongingness and connectedness**



# Effective ways of dealing with the COVID-19 situation

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- Some time people have other faulty appraisal such as their personal vulnerability, for e.g older people can have greater vulnerability to the virus and could be worse for them.
- Sometimes people do not have higher vulnerability, but they may start assuming that they are highly vulnerable to the virus or any kind of the outcome that the Pandemic can give.
- Such faulty appraisal can also be corrected which gives them the realistic picture of how vulnerable they are.



# Effective ways of dealing with the COVID-19 situation

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- Have a realistic estimation of the risk this will help one to be **CONCERNED and not ANXIOUS**
- Some people have underestimation of efficacy of simple techniques like washing hands, social distancing, these faulty reference and appraisals needs to be identified and corrected.
- Identify and write down your emotional and practical buffers and spend sometime to built some of these resources.
- Identify and write down the functional and dysfunction behavior eg Rumination is also a dysfunctional behaviors which should be stopped.





# Effective ways of dealing with the COVID-19 situation

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- **Information and Social Media**

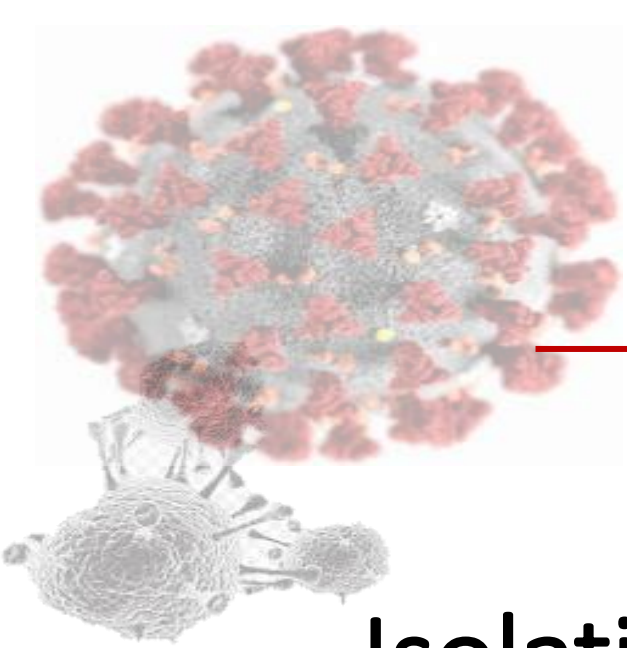
- Limit your sources from where people get the information from. As there is information overload about the COVID 19 Pandemic.
- Limit the time spend on the social media like researching, forwarding and reading the information. This is important, as there is a lot of conflicting information available, which gives lot of uncertainty.
- This can give triggers about anxiety if they have conflicting information or too much of information.
- Make a routine/plan of daily activities and follow it rigorously.



“Its not stress that kills us, it is our reaction to it.”  
-Hans Selye



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# Isolation: Being Alone but Not by Yourself: Navigating Through Feelings of Isolation and Social Distancing

Edward Kuebler, MSW, LLC



# What is isolation

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- Isolation:

- the state of being in a place or situation that is separate from others :
- the condition of being separated from other people, towns, countries, etc.

- <https://www.merriam-webster.com/dictionary/isolation>
- <https://dictionary.cambridge.org/us/dictionary/english/isolation>



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# Social distancing

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- the practice of maintaining a greater than usual physical distance from other people or of avoiding direct contact with people or objects in public places during the outbreak of a contagious disease in order to minimize exposure and reduce the transmission of infection

- <https://www.merriam-webster.com/dictionary/social%20distancing>



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This Social  
Distancing  
can also be  
isolating  
with no  
willingness  
to engage!





# Social distancing with engagement: makes all the difference!

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Add A Mask  
and Its All  
Good!

OK...  
You get  
where I am  
going with  
this!



What To Do With  
Feelings of Isolation,  
Fear, Loneliness?



# Isolation can remind us of.....

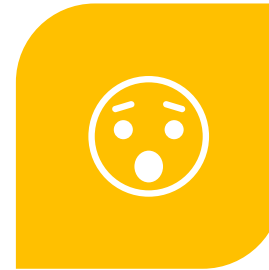
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**FEAR OF BEING ALONE**



**FEAR OF LOSING OUR  
SUPPORT**



**MEMORY FROM  
CHILDHOOD WHEN WE  
WERE ALONE AND  
SCARED**



**WE CAN BECOME STUCK  
IN FEAR WHICH CAN  
CREATE LONELINESS  
AND MORE ISOLATION!**



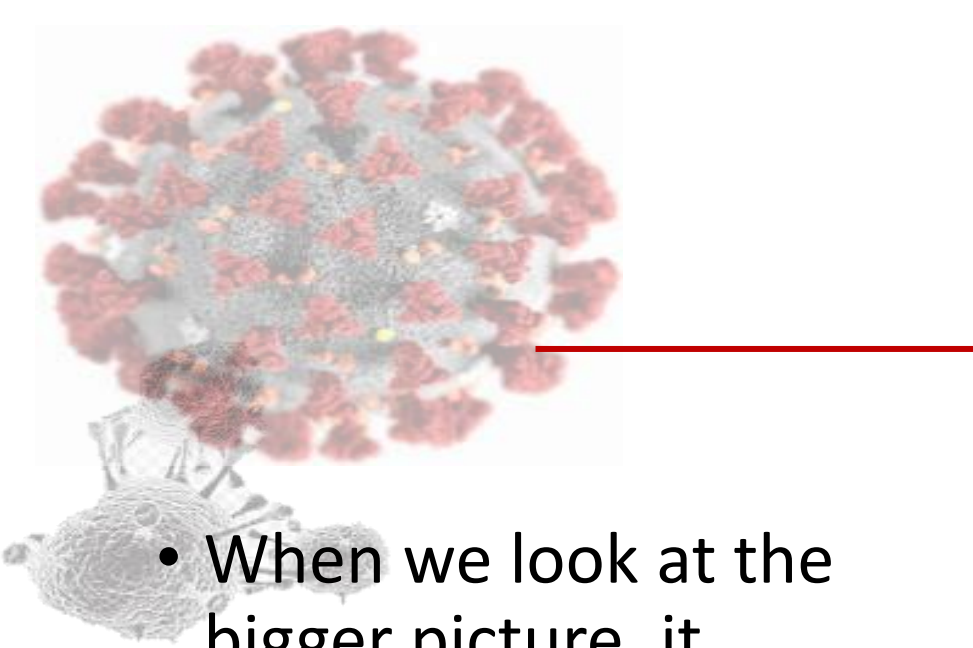
# Navigating through all this ....

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- Finding a new perspective:
  - Remembering we have the skills, this is not our 1<sup>st</sup> time going through something big!
  - Seeing beyond what is in front of us .....
  - Changing your outlook .
- Take a step back....or two.....







- When we look at the bigger picture, it opens up:
- more to see!
- more opportunities!
- a different perspective?





# Creating a new reality and normal

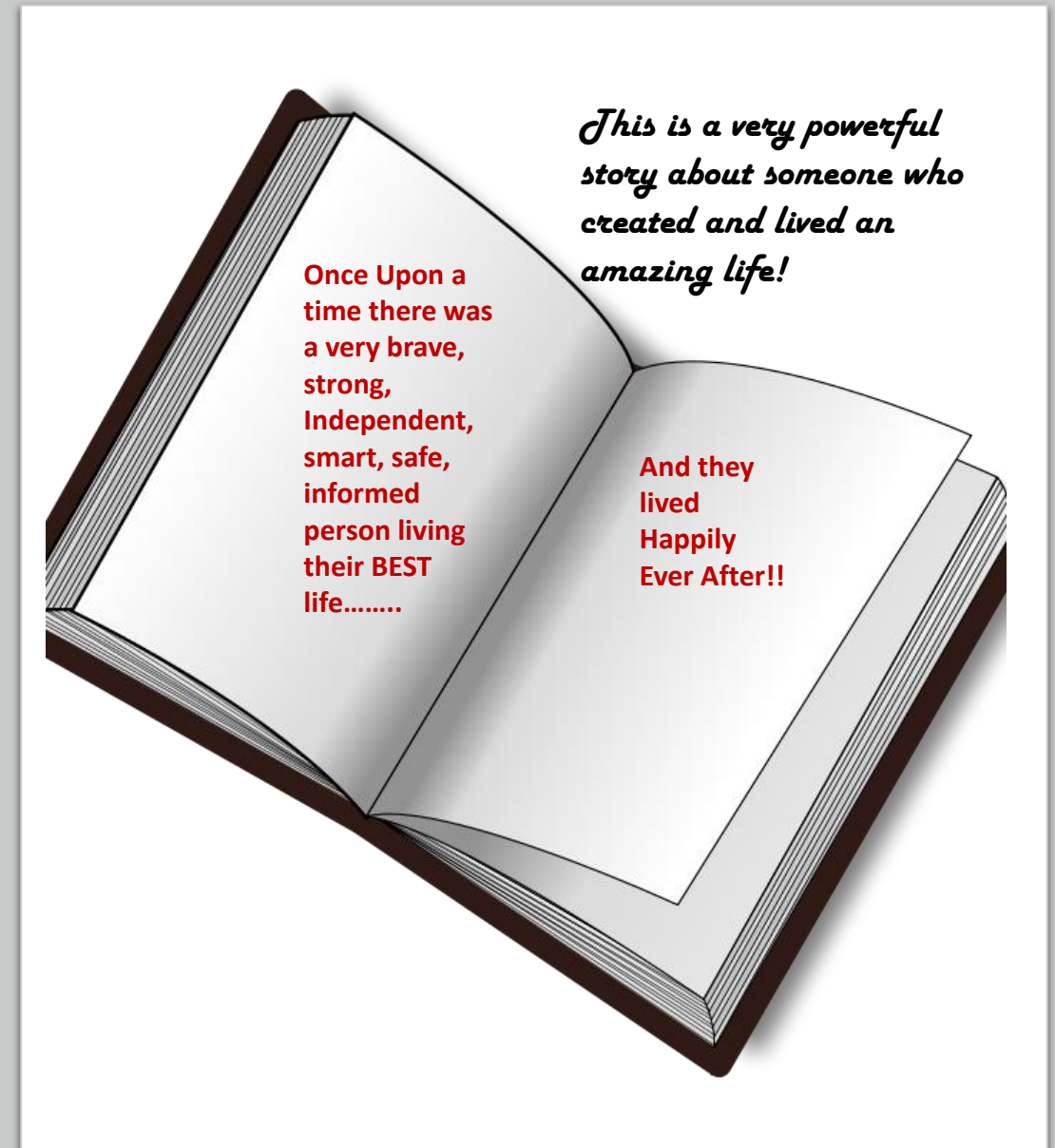
- Changing behaviors- do something different!
  - Imagination
  - Resilience
- Letting go of ***what you know*** to ***what is now!***
  - Creates movement
  - Creates possibility
  - Creates connection



# Create a new chapter in your life today!

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- All while:
  - Being **SAFE** – wear a mask, wash your hands (often)
  - Keeping **SOCIAL DISTANCING**
  - Stay **INFORMED**
  - **PROTECT** those around you
- **Write** the next chapter of your life:
  - Physically
  - Emotionally
  - Mentally
  - Spiritually
- Add color and details
- Now.....**Live** the next Chapter of your life!



# THANK YOU



**WITH SPECIAL THANKS TO**

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**HEMOPHILIA**  
**ALLIANCE**

Serving the Bleeding Disorders community since  
**1999**



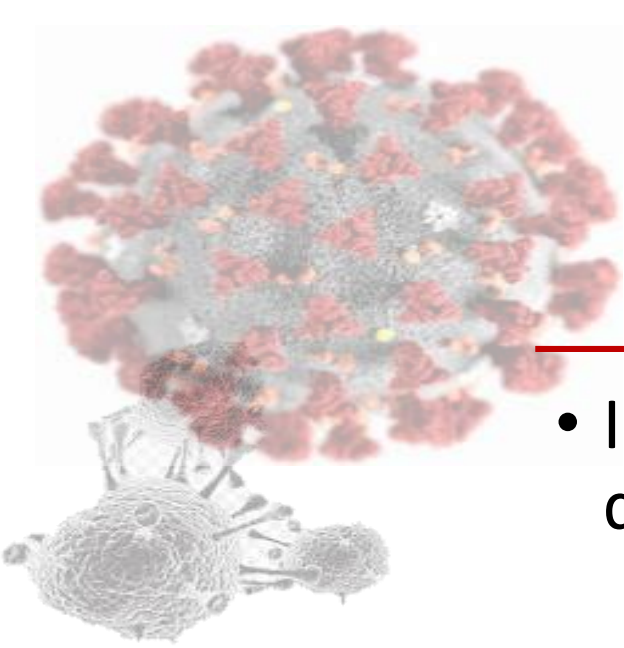
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# QUESTION & ANSWER PERIOD

Glenn Pierce, MD, PhD, Kate Khair, PhD, RN,  
Marlène Beijleveld, MSC, RN, Richa Mohan, MA.  
M.Phil., Edward Kuebler, MSW, LLC, Flora  
Peyvandi, MD, PhD



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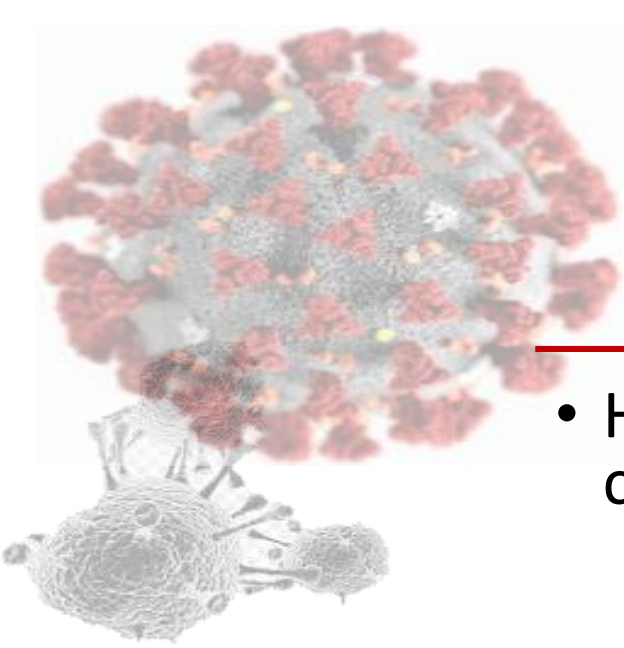


# QUESTIONS

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- I am very worried about the situation, what can I do to worry less? *RM*
- How can I overcome the mental stress from COVID-19 that results in skipping doses? *EK*



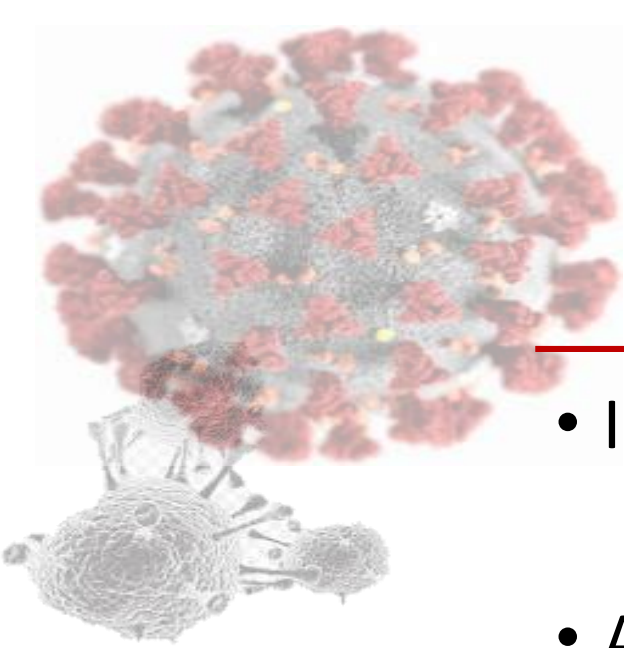


# QUESTIONS

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- How can I manage my fear and concern about my child/children? *RM*
  - MY child vs the population as a whole
- Do you have advice to help parents manage the different, scary news about covid-19? How can I deal with unknowns?
  - Many reports are coming out about Kawasaki syndrome *FP, GP*
- Should I change my child's treatment (increase infusion frequency?) *KK, MB, EK*





# QUESTIONS

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- I am getting restless at home, what can I do? *RM, KK*
- Are there psychosocial risks associated to the end of self-isolation/confinement? *EK*

WEBINAR

# STEPPING UP AND NOT STEPPING OUT

A NURSING AND PSYCHOSOCIAL  
PERSPECTIVE TO COVID-19



# STAY SAFE THANK YOU!

[research@wfh.org](mailto:research@wfh.org)



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