

WEBINAR

# YOUTH RESILIENCE DURING COVID-19

## *Staying Strong Together!*



Deon York (New Zealand)

David Salomón Cárcamo Bonilla (Honduras)

Jessica Page (U.K.)

Jodarsen P. Arnachellum (Mauritius)

Edward Kuebler (U.S.A.)

Stephanie Pineda (Canada)

Thursday, 3 September 2020



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

# SPEAKERS AND PANELISTS

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Deon York



Stephanie  
Pineda



Salomón  
Cárcamo Bonilla



Jessica Page



Jodarsen P.  
Arnachellum



Edward Kuebler,  
MSW, LLC



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# AGENDA

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1. Overview of the WFH Youth Leadership Program
2. Stories from the youth panel
3. Tips from a Psychosocial expert
4. Q&A

# ASK QUESTIONS

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The screenshot shows a Zoom webinar interface. At the top left, there is a 'Recording' indicator. The main content area features a red banner with the word 'WEBINAR' in white. Below this, the title 'YOUTH RESILIENCE DURING COVID-19' is displayed in a bold, sans-serif font, followed by the subtitle 'Staying Strong Together!' in a cursive font. To the right of the text is a 3x3 grid of nine video thumbnails, each showing a different person wearing a face mask. Below the main content area, there is a list of names and their locations: Deon York (New Zealand), David Salomón Cárcamo Bonilla (Honduras), Jessica Page (U.K.), Jodarsen P. Arnachellum (Mauritius), Edward Kuebler (U.S.A), and Stephanie Pineda (Canada). To the right of this list, the date 'Thursday, 3 September 2020' is shown. At the bottom right of the content area is the WFH logo, which includes a globe icon and the text 'WFH WORLD FEDERATION OF HEMOPHILIA FEDERATION MONDIALE DE L'HEMOPHILIE FEDERACION MUNDIAL DE HEMOFILIA'. At the bottom of the Zoom window, there is a control bar with icons for 'Audio Settings', 'Chat', 'Raise Hand', and 'Q&A'. A red arrow points to the 'Q&A' icon, which has a red notification bubble with the number '3' next to it. A 'Leave' button is also visible in the bottom right corner of the control bar.


Recording

WEBINAR

YOUTH RESILIENCE DURING COVID-19  
*Staying Strong Together!*

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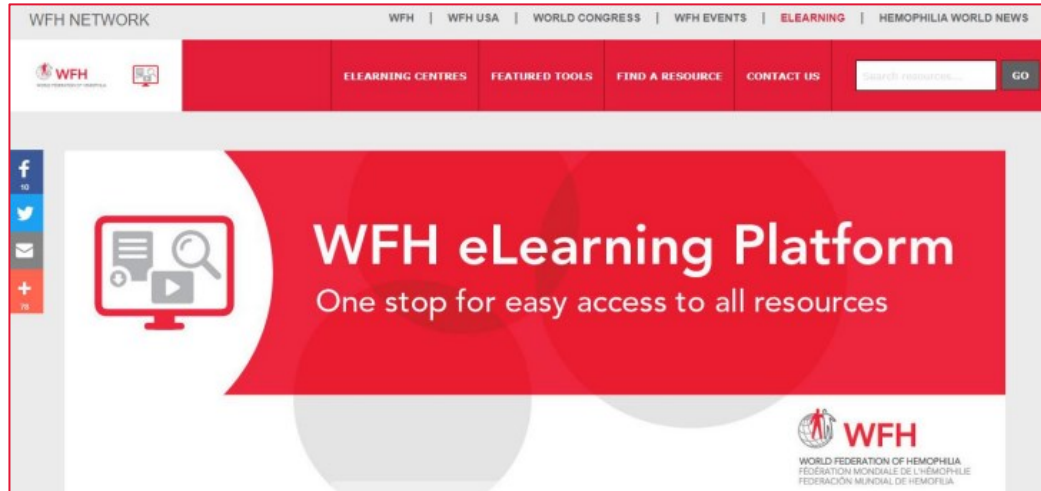
Audio Settings ^

Chat Raise Hand Q&A <sup>3</sup> Leave



# WEBINAR RECORDING

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A recording of the webinar will be available on the WFH eLearning Platform.  
The webinar will be made available in other languages.

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

# WFH YOUTH LEADERSHIP PROGRAM

Stephanie Pineda  
WFH Program Coordinator



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# YOUTH LEADERSHIP PROGRAM

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Cancelled

WFH Youth  
Fellowship Program /  
Susan Skinner  
Memorial Fund

Modified

Youth  
Leadership  
Workshop

Youth Group  
Twinning

Youth  
Committee

Educational  
Resources

# 1) YOUTH FELLOWSHIP PROGRAM

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- International competition
- Participation in WFH Global NMO Training, WFH World Congress, and Annual Meeting of the General Assembly
- 154 youth fellowships awarded to date



## 2) YOUTH WORKSHOPS: IN-PERSON

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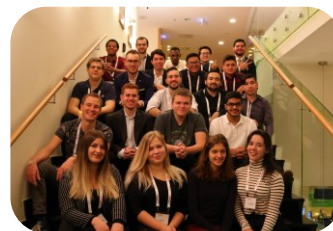
December 2013  
(Montreal)



December 2016  
(Barcelona)



July 2017  
(Panama City)



November 2018  
(Budapest)



March 2019  
(Bangkok)



September 2019  
(Montreal)



November 2019  
(Amsterdam)

## 2) YOUTH WORKSHOPS: ONLINE

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### Limitations:

- Less social interactions
- Access to computer and internet to participate

### Advantages:

- Safe!
- No visa necessary
- Everyone is invited
- Webinars are recorded

# 3) YOUTH GROUP TWINNING

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India – USA



Nepal – New Zealand



Dominican Republic – Georgia (USA)



Honduras – Mexico

## 4) YOUTH COMMITTEE (2018-2020)

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Nikole Scappe (USA)

Jorge Antonio Rodriguez (Panama)

Amanda Brito del Pino Mouro  
(Uruguay)

**Chair:** Michael van der Linde (Netherlands)

Rana Mahmoud (Lebanon)

Jodarsen Pillay (Mauritius)

Ashrit B.K. (Nepal)

Lauren Phillips (New Zealand)

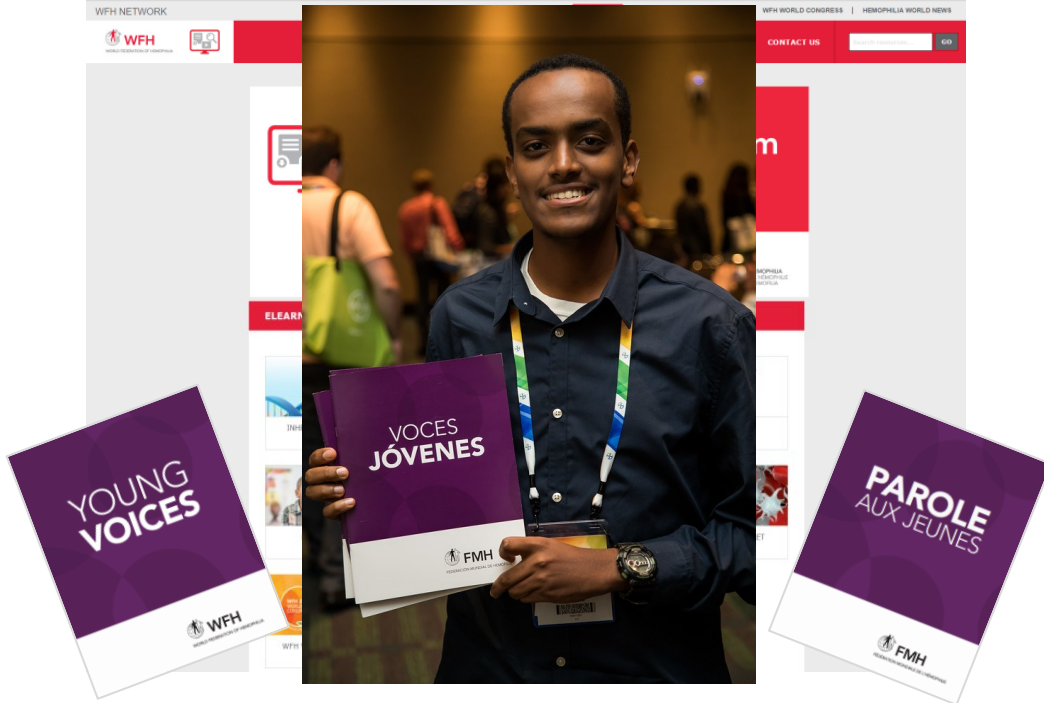


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## 4) EDUCATION MATERIALS

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- Articles (monographs) and Fact Sheets
- Patient Resources
- Guides
- Illustrated Handouts
- Books, Binders, Videos
- Card Games
- Online Training
- eLearning Platform
- Guidelines Development



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



**QUESTIONS & COMMENTS:**  
**PROGRAMS@WFH.ORG**

# YOUTH RESILIENCE IN HONDURAS

Salomón Cárcamo / Youth coordinator /  
Honduran Society of Hemophilia  
Juticalpa – September 3<sup>rd</sup>, 2020

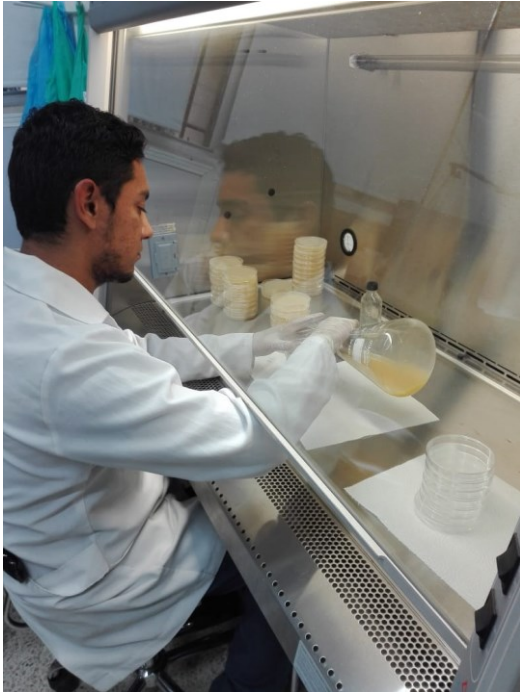


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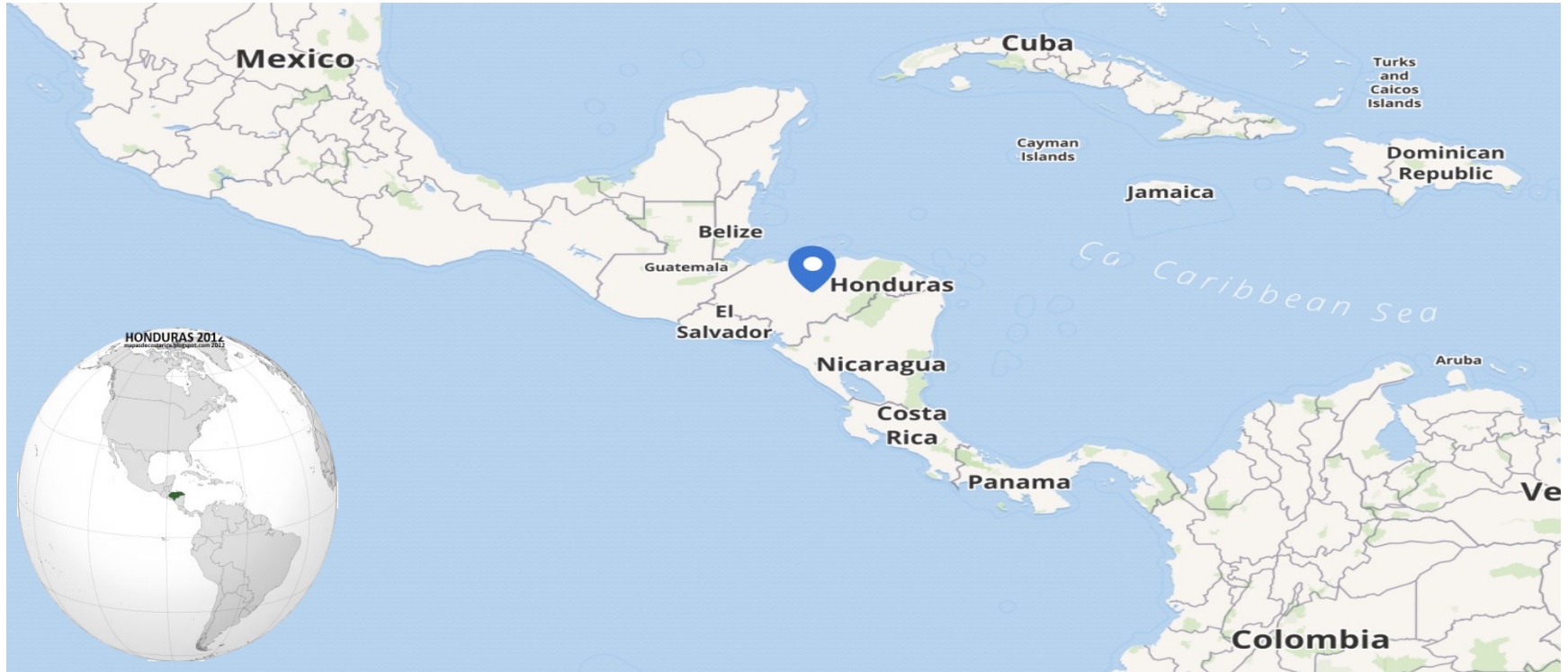
# WHO AM I?

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# WHERE IS HONDURAS?



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# BLEEDING DISORDERS IN HONDURAS

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## Patients distribution

HA	315
HB	35
VWD	20
FXIII deficiency	2
Unconfirmed	24
Total	398

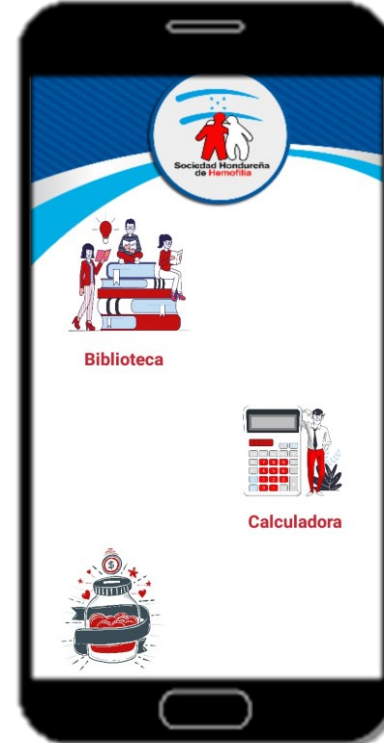


# BEFORE THE PANDEMIC

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# DURING THE PANDEMIC





# UNPRECEDENTED

Jessica Page  
Youth Ambassador  
The UK Haemophilia Society



# THE UK HAEMOPHILIA SOCIETY

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# THE HAEMOPHILIA SOCIETY

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**Lads and dads**  
Father and son activity weekend.



**Youth Camp**  
Action-packed activity weekend for children with bleeding disorders and their siblings.

**Newly Diagnosed Weekends**  
An informative weekend for families of children who are newly diagnosed. Last year over 30 families attended.



**Family Fun Days**  
Days at zoos etc for families affected by bleeding disorders: over 150 families attended last year.



**Talking Red**  
Campaign to raise awareness of bleeding disorders in women



# LOCKDOWN – 23<sup>RD</sup> MARCH

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Cancelled events: fundraising such as the London Bridge Walk and London Marathon; Talking Red event; Youth Camp; The Haemophilia Society's 70<sup>th</sup> birthday celebrations

Office closed

Vulnerable members of our community had to isolate, some still are.

I worked from home, homeschooling my class.

We are still in a partial lockdown



# OUR COMMUNITY

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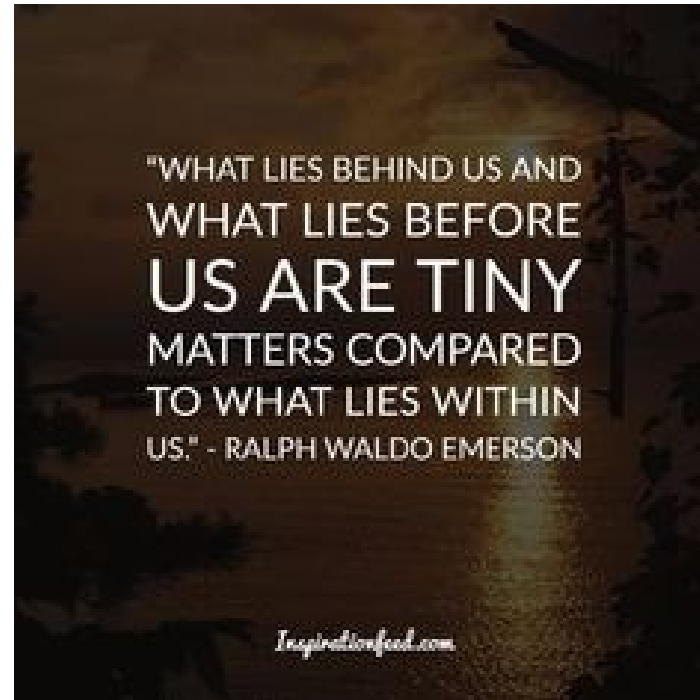
- Fundraising continues!
- Staff and volunteers working harder than ever to support our community
- Bleeding Matters Live webinars covering back to school, the public enquiry, peer review etc
- Knitting for Uganda
- Community survey into how Covid-19 has impacted them

**Bleeding  
Matters  
Live!**



# WE ARE CAPABLE

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"WHAT LIES BEHIND US AND  
WHAT LIES BEFORE  
**US ARE TINY**  
MATTERS COMPARED  
TO WHAT LIES WITHIN  
US." - RALPH WALDO EMERSON

*Inspirationfeed.com*



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# Overcoming COVID-19 Pandemic

Jodarsen P. Arnachellum

Executive Member & Youth Leader - Haemophilia Association of Mauritius

Founding Member & Vice Chairman - Haemophilia Youth of Africa

Member - WFH Youth Committee

MAURITIUS – Thu Sep 3 - Fri Sep 4, 2020



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# AGENDA

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1. NMO: Haemophilia Association of Mauritius
2. Haemophilia Youth of Africa
3. Covid-19 in Mauritius
4. Activities during the pandemic
5. Lessons Learned & Advices

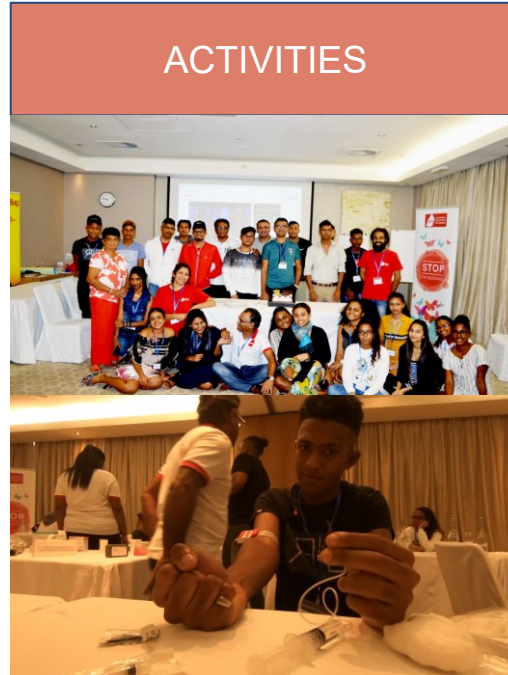
# NMO: Haemophilia Association of Mauritius (HAM)



## MEMBERS



## ACTIVITIES



## MY INVOLVEMENT



Mauritius Population  $\cong$  1.3M



# Pictures

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## HAM Youth Activities



## WFH Congress 2018



# Haemophilia Youth of Africa (HYA)

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ANGLOPHONE COUNTRIES

NMOS **10**

NOMINATED YOUTHS **20**



**HAEMOPHILIA**  
YOUTH OF AFRICA

FRANCOPHONE COUNTRIES



YOUTH VOLUNTEERS  $\cong$  **15**



@HaemophiliaYouthOfAfrica



@\_\_hya\_\_



@HaemoYouthAfric



Launching



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hemophiliaafrica@gmail.com



WIP



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# First Youth Leadership Training Workshop



# Covid-19 In Mauritius



## WEDNESDAY 26TH AUGUST 2020 COVID-19 STATISTICS MINISTRY OF HEALTH AND WELLNESS

DEATHS **10**

REGISTERED  
CASES **354**

ACTIVE  
CASES  
(Imported) **9**

SUCCESSFULLY  
TREATED **335**



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# Activities During The Pandemic

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STAYING STRONG TOGETHER!



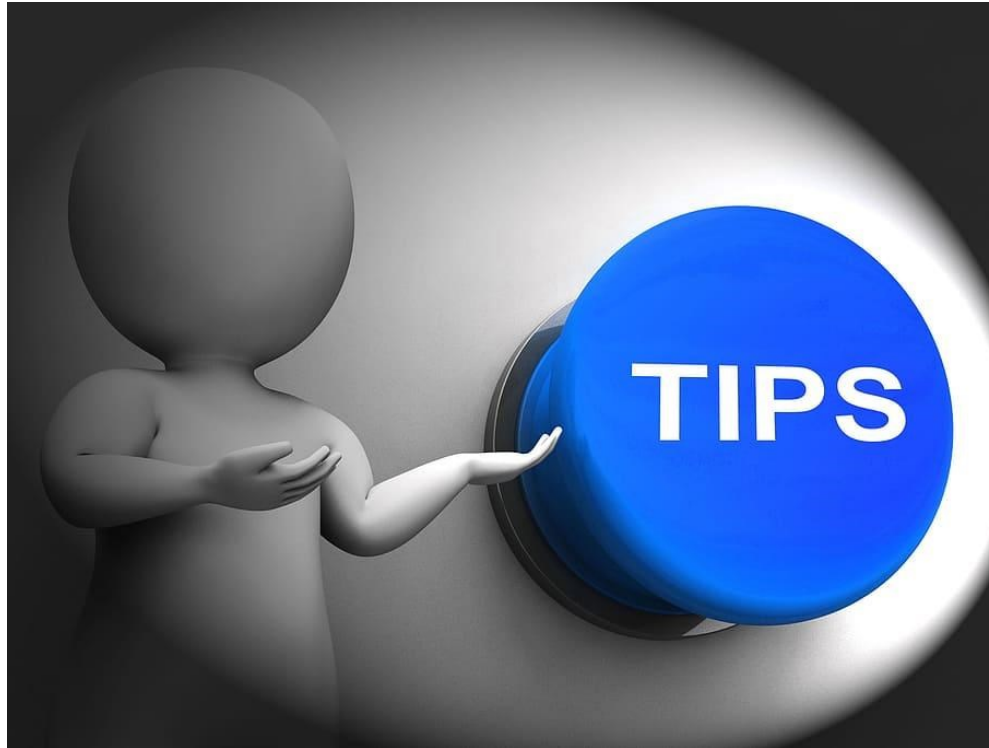
# Digital Content Creation

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# Lessons Learned & Advices

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**THANK YOU**



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# LIFE ON LIFE'S TERMS: Staying Positive And Optimistic

Edward Kuebler, BA, MSW, LLC – E Kuebler Consulting  
Global Blood Disorder Foundation, VWD Connect Foundation  
Lewes, Delaware, September 3, 2020



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# AGENDA

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1. Life on Life's Terms – Tools and Strategies
2. Staying Positive When Things Get Hard
3. Strategies For Changing Our View
4. The Power Of Choice
5. Meditation



# STAYING POSITIVE

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## Tools To Help Navigate Through Challenging Times

- Being positive is a perspective
- Positive VS Real
- Holding on to “old” truths



# STRATEGIES FOR CHANGING OUR VIEW

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## Strategies For Changing How We See Our World

- The lens of COVID 19
- Black & white or color?
- Glass half full or half empty
- Move your chair



# RAINBOWS AND UNICORNS

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# LIFE HAS A LOT TO OFFER

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- If we let ourselves see it, experience it, imagine it
- Life can hurt, leave us broken, afraid, hopeless but we do not have to live in that space, we can choose to move
- Life has endless choices

# THE POWER OF CHOICE

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One of the greatest  
**Superpowers** we  
have is...  
our ability to chose!

You have been  
honing this skill since  
birth

To chose nothing **is a  
choice!**



shutterstock · 744341656



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# THREE THINGS YOU CAN DO NOW

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1. Chose to stay positive
  - Make a conscious choice to not let your surrounding bring you down
2. Do something different or new today
  - Sit in a different “chair” in your house then you always sit in and look around
3. Identify 3 things or people you are grateful for
  - Gratitude diminishes negativity

# BEING GROUNDED KEEPS US SOLID AND STRONG

- Know who and what keeps you grounded (solid and strong)
- When we are grounded, we can fly as high as we want!



# 3-MINUTE MEDITATION EACH DAY

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# MEDITATION IS SIMPLE, FREE AND POWERFUL

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Quiet time

Close your eyes, take a deep breath, an another and with your third breath let go and relax into your body

Listen to the beating of your heart, follow the flow of your breath in and out... heart and breath each having their own rhythm

Allow any thoughts to float away like clouds passing in the sky

Introspective

Notice if you have any stress in your body.... Go there and breath into it and again begin to feel your stress lessen

Imagine a small white light in the center of your body, take a breath and go to that white light

Mindful

Feel its brightness, breath some of this light in

This is your light, the light of who you are and has been with you since you took your first breath

Rejuvenating

Breath into your light and feel it expand, let this light fill your body, let this light reveal your power and truth, let this light let you remember who and what you are grateful for

Let this light, your light be your guide as you walk through your day

Let this light remind you who you are.... Powerful, kind, strong, positive and filled with possibility

This is your light, take it into the world and let it be a beacon of hope, strength and positivity for you and others

Take a big breath into your body, come back to where you are sitting

Open your eyes and remember who you are, an incredible light in this world

# IF LIFE IS A BANQUET....

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**Fill Your Plate And Taste Everything!**



© HAP/Quirky China News/REX



# QUESTION & ANSWER PERIOD

Deon York  
Stephanie Pineda  
Salomón Cárcamo  
Jessica Page  
Jodarsen P. Arnachellum  
Edward Kuebler

WEBINAR

YOUTH RESILIENCE DURING COVID-19

*Staying Strong Together!*



**STAY SAFE  
THANK YOU!**



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