



# REVEALING THE BURDEN OF SEPSIS

For patients & their families

September 9<sup>th</sup>, 2024, Paris & Online



## PROGRAMME

9:30 am - 10:30 am: Welcome coffee

**10:30 am - 12:00 pm: Awareness & visibility**

12:00 pm - 1:00 pm: Lunch

**1:00 pm - 2:15 pm: (After)care for families & relatives**

**2:15 pm - 3:30 pm: Long sepsis?!**

3:30 pm - 4:00 pm: Goodbye session



## 10:30 AM - 12:00 PM AWARENESS & VISIBILITY

- Opening speech, **Dr Clément Lazarus** (Ministère de la Santé)
- ‘Sepsis, the unknown killer’, **Prof. Dr. Djillali Annane** (IHU PROMETHEUS & FHU SEPSIS)
- 2030 Global Agenda for Sepsis, **Dr. Mariam Jashi** (Global Sepsis Alliance)
- Increasing Sepsis awareness in Sweden, paralympian & sepsis survivor **Shahrzad Kiavash** (Sepsisfonden)
- Lil Red’s Legacy Sepsis awareness campaign, **Joe Hughes**
- Belgian pianist **Eliane Reyes** testifies about the loss of her partner, cellist Aleksandr Khramouchin, due to a Septic Shock



1:00 PM - 2:15 PM

## (AFTER)CARE FOR FAMILIES & RELATIVES

- **James Corcoran** about the loss of his beloved sister (Irish Sepsis Foundation)
- Support nurses for Sepsis patients: **Oliver Jones** (UK Sepsis Trust) and **Katelyn Walsh** (nurse & sepsis survivor, Irish Sepsis Foundation)
- **Jamila Hedjal** lost her young boy due to Sepsis (France Sepsis Association)
- ICU-diary & PICS(F), **Adeline Bultynck** (Belgian nurse)
- Meningitis & sepsis-survivors: paralympian & AEM-ambassador **Davide Morana** and **Aitana**, un unicornio brillante
- Listing unmet needs in the care/aftercare for families & relatives



## 2:15 PM - 3:30 PM LONG SEPSIS?!

- 'Invisible' Sepsis survivor **Marianne Haverkamp**
- **Simon Seyfarth** survived Sepsis as a baby, now a young adult at the Paralympic Youth Camp in Paris
- Challenges and opportunities for a national Sepsis patient organization, **Ilse Malfait** (Sepsibel), **James Corcoran** (Irish Sepsis Foundation), **Angels Garcia** (Stop Sepsis) and **Dr. Ron Daniels** (UK Sepsis Trust)
- From musical star to health entertainer, **Mariah McKimbrough** (Sepsis Stiftung)
- Call to action, **Sepsis Stronger Together**



# ORGANIZING COMMITTEE & SPEAKERS



Krista Bracke



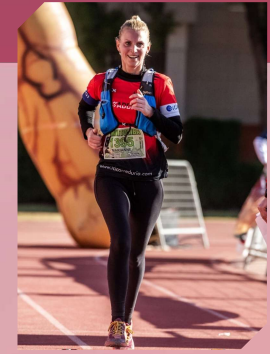
Elena Moya



James Corcoran



Eliane Reyes



Marianne Haverkamp



Oliver Jones



Mariah Mc Kimbrough



Katelyn Walsh



Shahrzad Kiavash



Ilse Malfait



## KRISTA BRACKE

*Sepsis survivor & Patient advocate*

- January 2009: Infected by streptococcus pyogenes bacteria, Krista bravely faced sepsis.
- Amputation: Despite the challenges, she emerged stronger, undergoing amputation of both lower legs.
- Reconstruction: Not one to back down, Krista underwent reconstruction surgery on her right hand.
- Primary Immunodeficiency: Her journey took another turn in December 2009 with a diagnosis of primary immunodeficiency.
- Survivor: Hailing from Belgium, Krista is a proud survivor of sepsis, embodying resilience and courage.
- Bladerunner: In 2015, she defied odds by embarking on her journey as a bladerunner.
- Patient Advocate: Krista's advocacy work at IHU Prometheus shines a light on the importance of patient empowerment and support.



## ELENA MOYA

*Meningococcal meningitis survivor & Patient advocate (AEM, Spain)*

Elena survived meningococcal meningitis as a child, a disease that can have sudden and severe consequences like septicemia. Thankfully, she emerged without lasting effects, and now, she's turned her experience into a mission.

Today, Elena is a passionate advocate for meningitis/Sepsis awareness. She coordinates over 15 patient organizations across Europe and tirelessly represents the patients' voice at the European Parliament. Her goal? To ensure everyone has equal access to prevention through national vaccination programs.





## JAMES CORCORAN

*Co-chairperson, Irish Sepsis Foundation*

James tragically lost his beloved sister to Sepsis, a silent and deadly condition that claimed her life too soon. She left behind two beautiful children and a heartbroken family, forever changed by her absence. The devastation of losing his sister has been incredibly hard on James and his family, but it has also ignited a passionate drive in him to ensure no other family has to endure the same pain.

James has channeled his grief into a tireless mission to educate Ireland about Sepsis. He has become a beacon of hope and knowledge, working around the clock to raise awareness of this critical health issue. Through powerful awareness videos and a nationwide campaign with the HSE (Ireland's leading health service), James has been instrumental in spreading the word about the symptoms and dangers of Sepsis in Ireland.

Belgium/France



## ELIANE REYES

*Concert pianist & Professor of piano at the Conservatoire National Supérieur de Musique et de Danse de Paris*

Eliane Reyes, a renowned Belgian pianist and esteemed professor of piano in Paris and Brussels, has touched countless lives through her music. But recently, she has embarked on a deeply personal mission that transcends the world of classical music. In 2023, Eliane faced an unimaginable loss when her husband, the celebrated Belarusian cellist Aleksandr Khramouchin, passed away suddenly at the age of 43. Aleksandr, who was the principal cellist of the Luxembourg Philharmonic, died from septic shock, a condition Eliane had never heard of before his passing.

The tragic and unexpected nature of Aleksandr's death left Eliane devastated, yet determined. She quickly realized that, like her, many people were unaware of sepsis and its deadly potential. Now, she is channeling her grief into raising awareness about this silent killer. "Very few people know about the symptoms of sepsis," Eliane says, "and that needs to change."

Eliane Reyes will be sharing her story and advocating for greater awareness of sepsis at the upcoming Sepsis Stronger Together event in Paris on September 9<sup>th</sup>. Eliane's story is a powerful reminder of how crucial it is to educate ourselves and others about sepsis, a condition that takes too many lives in silence.



## MARIANNE HAVERKAMP

*Founder of Sepsisinfo.es and member of the ESA family and patient workgroup and association StopSepsis Spain*

In less than 24 hours, Marianne's life changed forever due to severe sepsis/septic shock of unknown origin. Although her battle with sepsis is invisible to the rest of the world, it has left her on a bumpy and lonely recovery journey. The lack of information, conflicting advice from specialists, and feelings of isolation are experiences she wouldn't wish upon anyone.

Marianne is determined to raise awareness about sepsis and support fellow survivors, so no one has to feel as lost and alone as she did. Together, we can Stop Sepsis and make this battle more bearable.

Before sepsis, Marianne ran a successful catering company together with her husband on the beautiful island of Menorca. Unfortunately, they had to sell it urgently due to her health.

Running has always been Marianne's passion. After her sepsis ordeal, she fought back and trained extremely hard to be able to run again. Last year she triumphantly finished a trail run.

Join Marianne in raising awareness and supporting sepsis survivors. Together, we can make a difference!

United Kingdom



## OLIVER JONES

*Lead Support Nurse - UK Sepsis Trust*

Oliver is a dedicated Registered Nurse with over 12 years of experience in Critical Care and Acute Medicine. Throughout his career, Oliver has treated countless patients with sepsis and has witnessed the profound impact it can have on both patients and their families.

For nearly six years, Oliver has been a vital part of the UK Sepsis Trust, where he serves as the Lead Support Nurse. His role involves not just providing information but offering practical guidance to help sepsis survivors navigate their recovery journey. From telephone consultations to peer support groups, Oliver is there every step of the way, helping people overcome the physical, cognitive, and emotional challenges they face.

But his care doesn't stop there - Oliver also offers compassionate emotional support to families who have sadly lost loved ones to sepsis.

Germany



## MARIAH McKIMBROUGH

*Art Director German Sepsis Foundation (Deutsche Sepsis Stiftung), Stage professional, Coach, Entrepreneur and Best Selling Author*

Over 30 years of a successful stage career were tragically cut short. Multiple septic episodes, over 60 surgeries, two transplants, septic shock, and a coma changed the scene forever. It wasn't a long-term battle against an underlying disease, but the widespread and insidious killer "SEPSIS" that turned off the spotlight.

But this story doesn't end here. After connecting with the German Sepsis Foundation, Mariah, a former stage artist who also founded a state-registered vocational school for musical and entertainment arts, found a new purpose. With deep gratitude and humility, she realized that everything she had endured was ideal preparation for the most important mission of her life.

Today, we are honored to announce that this remarkable SEPSIS SURVIVOR is not only representing the German Sepsis Foundation as a special ambassador for performing arts and culture, but she is also their Art Director. She is responsible for the artistic-cultural implementation of the WHO Resolution "2030 Global Agenda for Sepsis."

Recently, her international project, S.O.S. STAGE of SEPSIS, debuted successfully in Nuremberg with the charity event "RHYTHM OF LIFE," taking the first steps towards raising one million euros for the 2030 Agenda.



## KATELYN WALSH

*Nurse & Sepsis survivor (Irish Sepsis Foundation)*

I am a registered nurse in Ireland with two years of experience in medical and surgical units. When I was 22, I was close to qualifying as a nurse with just nine weeks of training remaining. As a student nurse caring for patients, my life took an unexpected turn when I became critically ill and ended up as a patient on a ventilator in the ICU. It was one of the most traumatic experiences of my life.

Sepsis completely altered the course of my life. After being discharged, I expected to recover quickly, but I was wrong. I faced significant physical and mental challenges. Despite my nursing education, I had never heard of post-sepsis syndrome, and I received no information about it upon discharge. There is a glaring lack of awareness about this condition in Ireland. I was essentially left to navigate the aftermath of my illness on my own.

My goal now is to raise awareness among healthcare professionals about the seriousness of sepsis and its impact on patients and their families. I also want to encourage healthcare providers to offer comprehensive information upon discharge, ensuring patients understand what to expect when they leave the hospital. Currently, there is no support system for sepsis survivors and their loved ones in Ireland, and most patients are not followed up on after discharge. I am determined to change this.

I reached out to the Irish Sepsis Foundation because I wanted to help raise awareness about sepsis in Ireland. It's encouraging to see that there is a recognized charity dedicated to making a difference. Recently, I was invited to join the board and assist in their efforts to raise awareness.



## SHAHRZAD KIAVASH

*Sepsis survivor | Paralympian | Member of the board Sepsisfonden  
(Swedish Sepsis Trust)*

Shahrzad was 28 years old in 2012 when she was diagnosed with meningococcal sepsis. The doctors gave her minimal chance of survival.

She survived but had to undergo amputation of both lower legs.

Her story from amputation to the gym and all the way to Paralympics in Rio has been featured in media, TV and podcasts, both in Sweden and around the world.



## ILSE MALFAIT

*Sepsis survivor & Director of Sepsibel*

Four years ago, Ilse received her first chemo to overcome breast cancer. This caused a bowel perforation and she was rushed into surgery. The inhuman pain the day after the operation was normal, the doctor said, within a week you will be home. The week turned into 487 hospital days due to a septic shock, with all the visible (amputation of lower legs and fingers) and invisible sequelae (fatigue, concentration problems).

She wrote down her story to process it. The writing became a search for answers around sepsis, which she had never heard about before her illness. The more she read and learned about sepsis, the more hallucinatory she found it that a disease with so many victims and such serious consequences, is hardly named and known in her country.

Meeting other survivors of sepsis, attending the ESA conferences, discovering that many precious hours were lost in her file were the triggers to contact the Belgian media to make a television report on sepsis and to start the patient organization Sepsibel last year with a small group of other survivors.