Meningococcal: how a life can change in 12 hours

> Sarah Joyce 2023

The Beginning: Presenting to ED with a high fever, headache and vomiting.



Please be aware that you may find the following images confronting

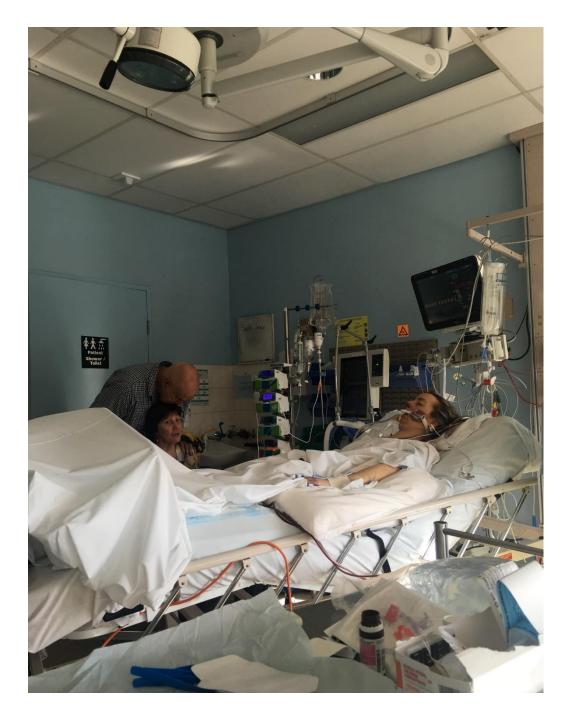


#### 12 hours later: Life support with a less than 5% chance of survival





## My family were told to say goodbye to me multiple times

















Waking up after 9 days. The damage done, but the fight to live was far from over...







**Central Coast Express Advocate** 7 mins · 🚱

Health warning after third case of meningococcal confirmed on Central Coast in 2016. It comes after 30-year-old Sarah Joyce (pictured) was struck down by the disease six weeks ago.



Health warning over meningococcal dailytelegraph.com.au

PRIDE OF AUSTRALIA 2010

Brave battle to overcome

# deadly meningococcal virus

Sarah Joyce spent eight days on life support after contracting meningococcal. Now the 30 year old has woken up and is amazing everyone around her with her will to live.

Sarah Joyce at her 30th birthday celebrations before she was struck down with the meningococcal disease last month. Inset: Sarah on life support in Gosford Hospita

Sarah shows amazing courage under fire with friends and family in

Disease numbers on the decline

Denice Barnes

COASTWIDE

WEDWESDAY, SEPTEMBER 7, 2016 EXPRESSAP

Express Advocate the amount of people dias sed with meningococcal the past 20 years from an average of about 15 cases a two children from the disease, seven-year-old Stephen Sanig in 2001 and seven-venr-old Rebecca Calverly in 2002. Central Coast Local Health District's public health director Dr Peter Lewis said there had been two cases on the Coast in 2015 and four in 2014, while so far this year there had been two cases, one in July In NSW, there have been cases so far this year, with



Sarah Joyce in Gosford Hospital following surgeries to amputate parts of her fingers after she was who just a short time ago celstruck down by the meningococcal disease. Inset: Sarah before she was struck by the viry

cluding her mum and dad. Karen and Garry, of Wam-IUST over four weeks ago beral, her brave attitude con-30-year-old Sarah Joyce was tinues to amaze everyone. rushed to Gosford Hospital "She's had nurses and docwith extreme flu symptoms. tors in tears, shocked and re-

was given the diagnosis

Coast this year.

gery on her toes.

down the track.

meningococcal, just the sec-

ond case on the Central

That week Sarah was one

nosed with the deadly virus.

first admitted she was given

the right antibiotic to treat meningococcal and the

teams at Gosford Hospital

her." sister Karly Joyce said.

In a matter of 12 hours, her lieved at her progress and Her family was told she how she's fought with everybody had shut down. might not make it and called thing she has ... barely a cominto her room at each critical plaint," Karly said. "She's extremely strong point in case it was the last willed and is the toughest time they would see her. girl we know. We will prob-After five days the family

ably never know how she contracted the virus, it was most likely airborne, through a cough or sneeze. Sarah and her family are keen to raise awareness of of five across the state diagthe virus saying people need "Luckily when Sarah was to act quickly if they suspect they may have contracted it. "If you don't act quickly, it can be too late." Karly said. Sarah has a long road worked rapidly to assist ahead of her, including dialysis three times a week After eight days on life while waiting for a transsupport, Sarah woke up, plant, and it is only just start amazing everyone around ing to sink in.

her. She is off life support "She will need to slowly and has undergone a num- learn to stand and walk ber of amputations that have again and is now building affected her right hand and strength with physic each will soon undergo more sur- day," Karly said. A GoFundMe page has

When she is strong been set up to help Sarah enough, she will need to with the financial realities have her spleen removed she will face in the future. and a kidney transplant "We've had so many peo-

ple offering support," Karly While it was a shock for said.

everyone who knew Sarah, You can help by visiting gofundme.com/











## The Long, Hard Road to Recovery continued...





#### Dad slept on the floor of ICU for two months!







## Many ups and downs – to leave ICU after over 80 days



## FINALLY HOME! But not for long...





The next chapter begins.....

### 7 years of constant fight, this is my story



In August 2016, I began to feel unwell with flu like symptoms.



Symptoms and progression of symptoms.



Emergency Department experience.



Strain of Meningococcal identified 4 days into coma.



Immunisation? - the most common question I am asked.

- In ICU my heart was failing, and my lungs filled with 3L of fluid.
- Everyday, something new presented.
- I was put back on life support a further 5 times.
- Operations began whilst in ICU and have continued up to
  September this year – 7 years on.
- A total of 70 surgeries/procedures.



## **Surgeries**

Removal of Spleen, gallbladder & large bowel

Formation of ileostomy plus reversal

Initial Finger and toe amputations - plus revisions and further amputations.

5 Laparotomy surgeries due to bowel obstructions – 2 of which occurred this year

Kidney Transplant in 2020

Multiple insertions of feeding and peg/pej tubes in abdomen.

Insertion and removal of failed catheters for attempting Peritoneal Dialysis.

Multiple Central lines – at least 30

Formation of AV Fistula for dialysis – revised 7 times.

Dialysis CVAD – multiple

Vascular surgery to ligate AV fistula and thrombosis x2.

Venoplasty

Multiple scopes

Dialysis: My kidneys failed completely during the early onset of Meningococcal and would never recover





Haemo Dialysis – 3 days a week. Five hours a session to stay alive for four years.





The mental health impact.

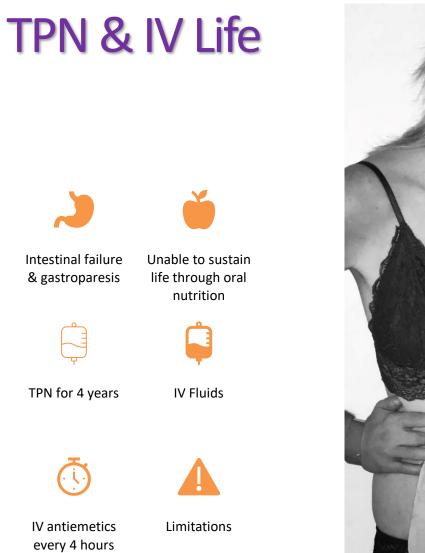
#### Life Saving Kidney Transplant

- 1<sup>st</sup> August 2020 I received THE call
- Proudly named Little Ripper
- Immune suppressant medications
- No more dialysis!!



## Hospital Admissions: Approx. 250.















## ADVOCACY



Sharing my recovery so publicly in the hopes of saving others from this cruel disease



Billboard & buses outside Parliament House



Social media



Advocating for change – ACWY

### Advocacy





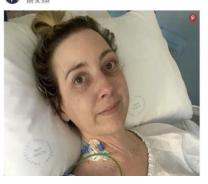




Sarah thought she had the flu. Within 12 hours doctors were telling her family to say goodbye.



{REAL LIFE}



NSW Health NSW @NSWHealth

Today is **#WorldMeningitisDay**. Meningitis is a rare but serious and sometimes fatal infection. Find out more in our factsheets for meningococcal disease, Hib disease and pneumococcal disease:

health.nsw.gov.au/Infectious/fac...

## Meningitis can affect people of any age. Symptoms of meningitis often appear suddenly and can get worse very quickly Image: Sudenly and can get worse very quickly Image: Sudenly and can get worse very quickly</td

#### NSV

Australia: <u>Sarah Joyce</u> sent CoMO's call to action letter to a MP to ask him to support the campaign. He sent her a supportive letter back, attended her High Tea event and NSW Health recognised the day for the first time ever!

## **NSW Parliament**

- Meningococcal B Advocacy with my mother, Karen the CEO of Meningitis Centre Australia and Stacey who lost her son to MenB last November.
- Spent 2 days in September with positive discussions with MP's from all parties regarding the need to prevent deaths and disabilities.
- The importance of adding MenB to NSW State Immunisation Plan funded for infants & teens.
- B The Change For Brayden



# Where to from here:

- Living on TPN permanently
- Severely immunocompromised
- Recurrent hospital admissions
- Anti-rejection medications for kidney transplant
- Continue studying Bachelor of Public Health
- Campaigns & projects



Connect & Follow my ongoing journey via:

Instagram: @iamsarahjoyce\_

www.facebook.com/sarahsrecovery2016

www.championhealthagency.com.au

