

UK CRITICAL CARE RESEARCH
FORUM

MANCHESTER

JUNE 2015

WHO AM I?
WHAT HAPPENED?
EXPERIMENTS/TRIALS?
QUESTIONS?

WHO AM I?

- Norman Druce born 1949 in Salford
- BSc(Hons) Chemistry 1971 (Manchester)
- Married Kathryn 1977, live in North Manchester, 2 children (30s) and 2 grandchildren all living in London
- Medical Representative since 1980
- Guillain Barre Syndrome Nov 2012. 57 days ventilated, 59 days in ICU. Came home June 2013. Not worked since then
- Retired Sept 2014 (age 65)

WHAT HAPPENED?

VENTILATED & PARALYSED

Sedated:- Dysautonomia

Arrhythmias BP ↑↓↑↓

WHEN AWAKE:- FELT AS
IF LOCKED IN A
CONCRETE SUIT TOTALLY
UNABLE TO MOVE

**BUT BRAIN ACTIVE AND FULLY
COGNISANT OF PEOPLE &
SURROUNDINGS**

PHYSICAL ISSUES

- ROLLING
- CONSTIPATION
- SUCTION
- PASSIVE
PHYSIOTHERAPY
- THIRST
- FELT VERY HOT
- ENOXAPARIN 1.4ml
S/C 6pm
- EMG

MENTAL ISSUES

- VIVID DREAMS, HALLUCINATIONS, NIGHTMARES. They all seemed very real. Felt very confused when I woke up in ICU. "I CANT BE HERE BECAUSE I'VE JUST DIED IN AN INFERNO!!" Due to VENTILATION? Or BEING IN ICU? Or HAVING GBS? Or DRUG INDUCED? Or ANY or ALL 4?
- FRUSTRATION-PARALYSED BUT MENTALLY ACTIVE Count ceiling tiles, multiplication, Morse Code
- ALARM Dit Dit Dit Dah Dit S N "STOPPING NOW"
- MOBILE X RAY everyone leaves the room but ME!
- **COMMUNICATION** ➔TE TE & LIPREADING ➔PASSY-MUIR VALVE

EXPERIMENTAL TREATMENT

- IN NORTH MANCHESTER GENERAL ICU I WAS NOT OFFERED ANY EXPERIMENTAL TREATMENT. NEITHER WAS KATH!!
- APART FROM VENTILATION AND ROUTINE CARE, **CURRENT GBS THERAPIES ARE: IVIG (2 courses) AND/OR PLASMAPHERESIS.**
- HOWEVER I **DID** HAVE A 3 DAY COURSE OF IV METHYLPREDNISOLONE? **THIS IS NOT INDICATED**
IN GBS!!

ATTITUDES TO TRIALS (HYPOTHETICAL!)

- ME: If offered I would have consented immediately especially when I was at my lowest! I would be more interested in possible benefits v risks!
- KATH: Probably more cautious and questioning about potential risks

WE FEEL IT IS VERY
IMPORTANT TO INCLUDE
THE PATIENT AND/OR
CARER IN THE DECISION
MAKING PROCESS ON ALL
TREATMENTS

QUESTIONS?