



**We Care Journey**

#thinkSMALLactBIG

# **MARIM International Conference**

**20 – 21 August 2019  
Le Méridien Putrajaya**

**Speaker: Edmund Lim**

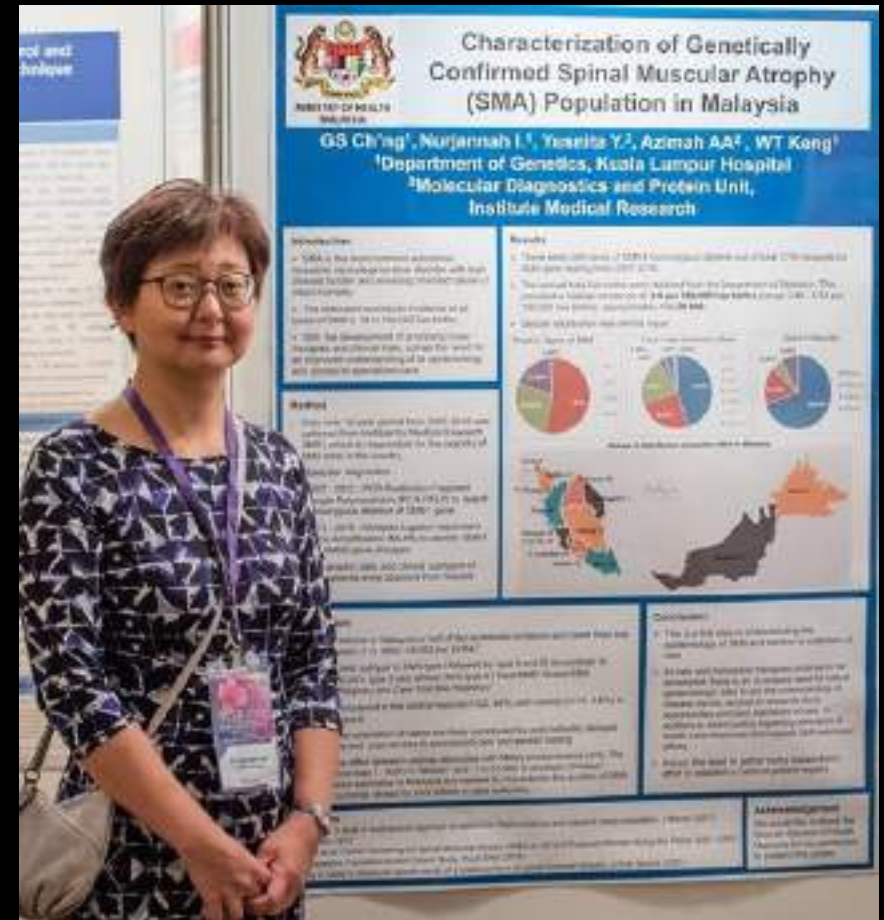
# Risk of Spinal Muscular Atrophy (SMA)

Genetic neuromuscular disease

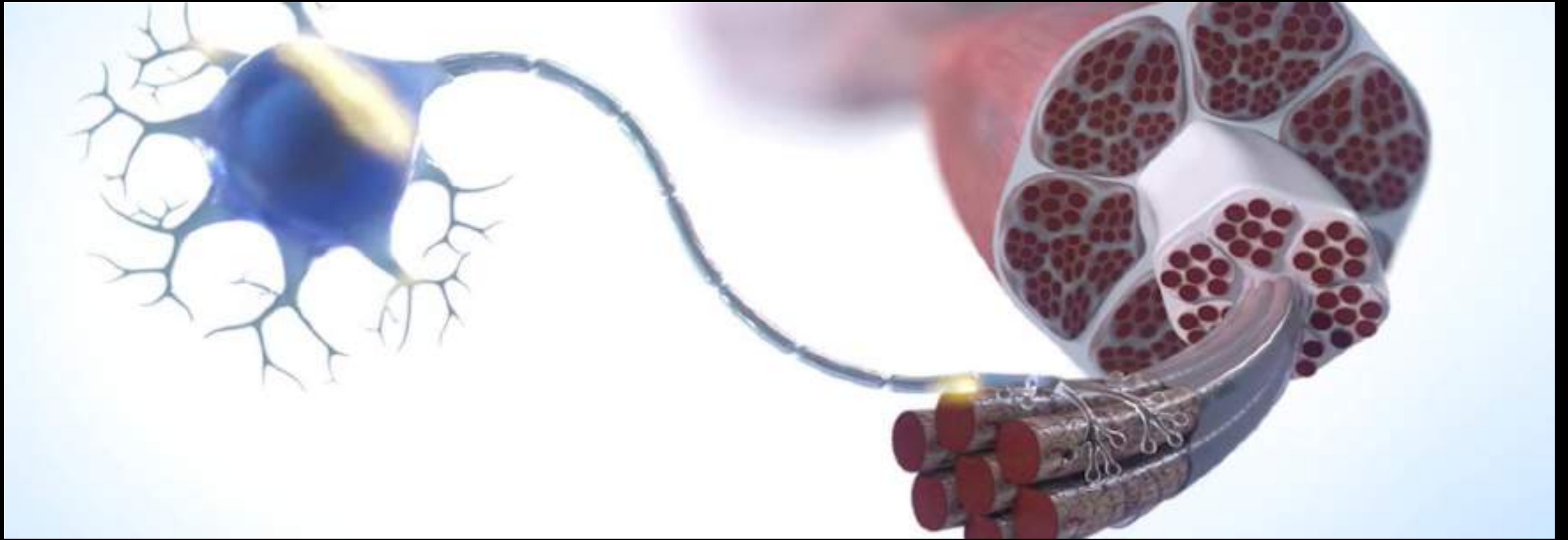
Incidence of *at least* 1 in 20,000 live births

More possibly, ~1 baby born every week

*How many survive?*



# SMA – nerve cells (motor neurons) die causing muscles to waste away (atrophy)



# Catastrophic burden of SMA

Types 1 (most severe) to Type 4 (mild) depending on best function achieved, and age of onset & severity

#1 genetic cause of death of infants - most do not make it past their 2<sup>nd</sup> birthday

Progressive & degenerative

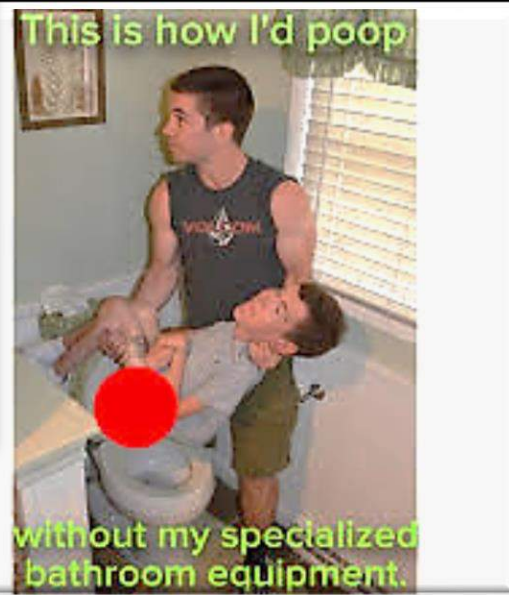
Eventually lose ability to move, talk, eat, & breathe...

# Branden and our Journey

Milestones missed  
"Take him home and love  
him" Something wasn't right



# What lies ahead – keeping on top, and...



# Risk of SMA to you or your loved ones

Planning to have a baby? Know that:

- 1 in 50 people are carriers of the gene that causes SMA or ~640,000 Malaysians
- If both parents are carriers, every pregnancy has 25% chance of baby affected by SMA

# Since Dec 2016, SMA doesn't have to be terminal

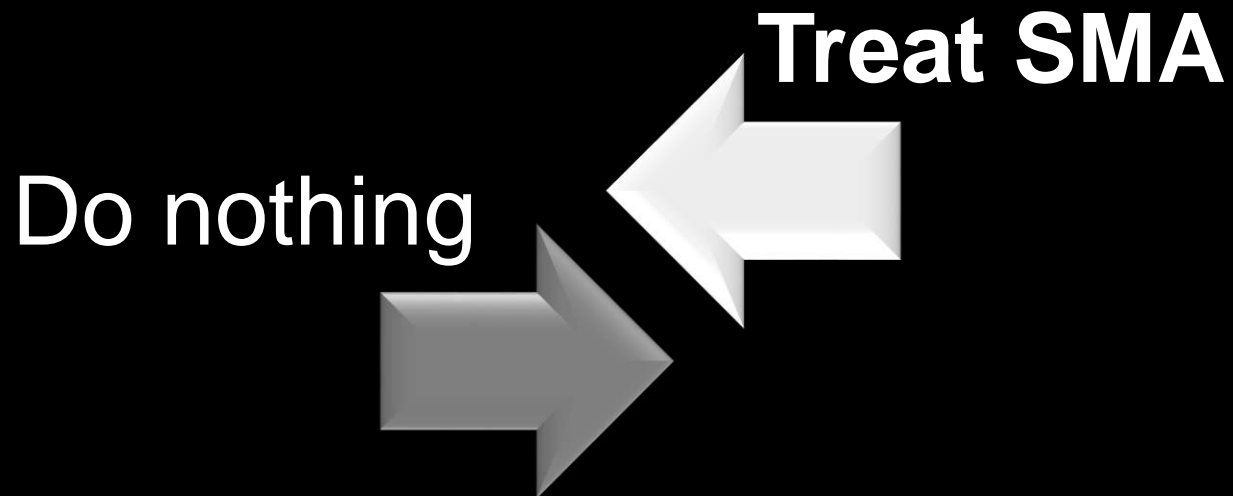
- New drug therapies stop SMA
- ~50 countries provide Spinraza



- But patients here cannot self insure
- Highly vulnerable sma-II populations are marginalized and left behind



“Sustainability meeting the needs of the present without compromising the ability of future generations to meet theirs”



# CARE & CONNECT

## EDUCATE & EMPOWER

### LEARN to Care for SMA

- Flyers
- Digital Outreach
- Bahasa Malaysia, English and Chinese Care Guide
- Medical Talks with Experts



### PROTECT from Illnesses & PREVENT Mortality

- Mechanical insufflation-exsufflation machines
- Vaccinations
- Standing frames



### EMPOWER Patients & Care Givers

- Fund for assistive equipments
- Parents Support groups
- Programs & platform for personal & professional development



# ACTION & AWARENESS

WeCareJourney creates awareness to the public on SMA and other disabilities through inclusive events, social media and other media channels.



# READY & RESPONSIBLE

### WeCareJourney focus on

- Initiate and engage with government and related bodies, pharmaceutical companies, payors and medical community to ensure there is inclusion and **access to medicines**.
- Inititates and sponsors **research projects**
- Develop ongoing relationships with overseas SMA experts to build capacity in Malaysia to **raise standards of care**.

We help connect patients from Malaysia and ASEAN into clinical trials. Please contact us for Type1 babies and children @ **+6012-2395592**



We Care Journey

#WITHSMALLWHEELS



MAKE A DONATION

We Care Journey

# Join us on this **SMALL** mission

and make a BIG difference

**Support** visit Ainaa's booth  
**Mention** to people  
**Adopt** us 😊

[www.WeCareJourney.org](http://www.WeCareJourney.org)





Thank  
you