

I have spina bifida and what this means to Malaysia

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1.0 THE DRAMA OF THE INTRO

In December of 2002, the Malaysian government sent one very highly opinionated individual with spina bifida to do her PhD on her medical condition at University College London (UCL) ([Abdul-Aziz et al., 2009](#); [Mohd-Zin et al., 2017](#); [Pai et al., 2012](#)). Truth be told, in retrospect, during the phone interview with Professor Andrew J. Copp, this particular Malaysian student was not aware that her would-be PhD supervisor at that time most likely may not have considered the extent of the severity of her disability ([Pit-ten Cate et al., 2002](#); [Sahmat et al., 2017](#)) and the extent of having to deal with an individual with needs, different from other postgraduate students. UCL and England, being champions of equal opportunity ([UCL Equality, Diversity, and Inclusion, 2017](#)), the focus during the London-Kuala Lumpur phone interview was entirely on her laboratory experience ([Master of Science Thesis at UKM: Pengklonan Gen Neuropeptida dan Analisis Filogeni, 2002](#)). The individual knew one thing and one thing alone, that she wanted to be regarded as capable purely on the basis of her academic abilities, and keenness on the topic and that she knew she had a huge plus on her side, that the [Malaysian government would finance her studies](#) (being of Bumiputera status by virtue of her mother's ethnicity) and having passed all the relevant exams and that all she needed to do was to make the case to procure a PhD studentship from a top global university.

It has been more than 10 years since the above said individual completed her PhD in Neural Tube Defects (NTDs) where she studied the mechanism of adhesion and fusion of spinal neural tube closure ([Abdul-Aziz et al., 2009](#)). NTD is defined by embryologists as the failure of neural tube closure and can exhibit either one of these 3 important phenotypes: craniorachischisis, anencephaly and spina bifida. Clinicians and surgeons would claim that the condition is even more severe with the added phenotypes of encephalocele and iniencephaly ([Botto et al., 1999](#)). An NTD is a devastating condition and is the leading central nervous system malformation in humans, with 1-10 in 1000 births worldwide ([Mohd-Zin et al., 2017](#)). In this story, the above said individual is me. I have suffered the consequences of lipomyelomeningocele (whether this is defined as a closed NTD or a spinal dysraphism or can be regarded simply as spina bifida occulta remains debatable) with neurological deficits since birth with an L3 lesion (interestingly, the first Magnetic Resonance Imaging of my brain and spinal cord only took place in 2005 when I was 30 years old at the Institute of Neurology in Queen's Square WC1 London). Prior to that, it repeatedly clerked in my patient records that I have an L5-S1 level of lesion (does it matter, really?). I am the oldest surviving person in the world with spina bifida, who also has had a permanent ileal conduit since the age of three. An ileal conduit persisting for 43 years post-procedure is unheard of. No publications exist on persons with ileal conduit surviving beyond 15 years after the procedure ([Madersbacher et al., 2003](#); [Westney, 2010](#)).

The birth of a child with NTDs has often been described as something close to catastrophic when it happens to families. So how is it that some families do well and others do not ([Kanaleswari et al., 2011](#); [Ong et al., 2010a, 2010b, 2011](#); [Pit-ten Cate et al., 2002](#); [Thong et al., 2019](#))? I remember the hours late into the night reading papers collected by Professor Andy Copp on patient family experiences. We were only allowed to read them in the office and not bring the papers out. So, I would stay late at night to read in the Institute of Child Health London office, and I often cried alone, reliving how ghastly it must be for parents to be told such horrendous news that their child will live but also experience all manner of things that will forever be wrong until adulthood. I remember the conversation I had with **Professor Zaliha Omar** as a 14-year-old teenager, "Sorry, you will become worse, and the wheelchair will eventually be unavoidable," and with all my might, I threw my crutches at her with utter disgust and contempt. Our relationship survived.

NTDs are a mouthful for the scientific and medical community. There is a whole range of undefined terminologies which escape the very people to whom the education of this condition is tantamount ([Bannink et al., 2016](#); [Lindsay et al., 2016](#)). The biggest mouthful (in my 5-10 years or so of running a support group known as [Malaysia Neural Tube Defects \(Malaysia NTD\)](#)) are the words myelomeningocele and lipomyelomeningocele. These words wreak terror in the hearts of parents when informed by the doctors. The rush to google those words quickly disintegrates into horror when they realise that they are not even able to spell those words, let alone digest these wholly new words into their vocabulary in five seconds; these words, which will oft be repeated time and again, episode after episode, from one emergency room to the other ([Riddle et al., 2019](#)).

2.0 THE FALLACY OF LACK OF INTELLIGENCE

Every child born with spina bifida, especially the non-syndromic version, should have a typical functioning brain of average intellectual quotient and should not be considered a person with diminished intellectual capabilities ([Schneider et al., 2021](#)). This is not to say that there does not exist radiological imaging of brains belonging to people with spina bifida, which accrue to changes such as dysgenesis of the corpus callosum ([Schneider et al., 2021](#)). However, how significant and proportion of the spina bifida community this holds water remains unknown and is poorly studied ([Rossi et al., 2004](#)). However, I spent the greater part of my youth having to justify that I deserve equal rights as any other

child my age. I had to prove that I was smart at every juncture and that I had a working brain ([Lomax-Bream et al., 2007](#); [Schneider et al., 2021](#)). Therefore, my claim to an equal education is legitimate; that I should be given the same opportunities as my non-disabled counterparts; the odd bits and bobs of me, such as knee-ankle-foot-orthoses and axillary crutches ([Ivanyi et al., 2015](#)), should not be held against me. It is exhausting to prove to adults when ONE IS STILL VERY MUCH ONLY A CHILD that my passion and interests can be as diverse as any other child in my age group. It is incredibly exhausting to be made to validate oneself at every juncture, that my teachers include me in school activities, such as my opportunity to sing at the National Day celebrations in 1989, eventually side-lined by a somewhat bigoted singing teacher (bad things happen even in convent schools run by nuns).

When the Disability Act of 2008 was presented in Parliament in 2008, I was a newly minted PhD. The minister of Women, Family and Community Development at that time was beyond eager to be photographed with me. I declined. I made a promise many years ago that if I were to make it through the Malaysian education system and get through higher education, I would never trade my scruples even for all the gold in the world. I knew then and as I know now that in the depths of Malaysian politics and governance, people with disabilities, especially those arising from birth defects are at the bottom most of the barrel of society. The stench of rejection is almost enough to make any Malaysian child born with a birth defect climb back into his or her mother's womb for safety. It is a known fact that in Malaysia when the back of a baby with spina bifida, especially those with spina bifida aperta, is closed by anyone other than the most experienced neurosurgeons, what happens is that the downstream effect is catastrophic not just to the individual with spina bifida ([Malaysia NTD Day 2](#)) but also costly to society. The estimation of expenditure by the State clocks in at RM 20,000 for a child with spina bifida without complications and the state has been known to spend close to RM 120,000 for a child with spina bifida who have a myriad of complications. I refer to the excellent and most honest presentation by **Dr Neoh Siew Hong** (Kementerian Kesihatan Malaysia). Malaysia NTD is also joined by Malaysia's most eminent health economist, **Professor Asrul Akmal Shafiei**. I am always in awe of the Almighty's people put in my path. Their story usually reverberates with mine in such a kindred spirit. **Asrul** shared with me stories when he was a PhD student in England, and I knew right then that I had found the right collaborator to embark on such an

important topic as Health Economics of NTDs in Malaysia.

We in Malaysia NTD have the services of not one but four neurosurgeons: **Associate Professor Azizi Abu Bakar, Professor Dharmendra Ganesan, Mr Azmi Alias and Associate Professor Kamalanathan Palaniandy**. We veer towards being more aggressive in our management of spina bifida in the footsteps of Professor Michael K Morgan, opting for elective surgery to address untethering of the spinal cord before the age of two. This decision is based on our observations, especially amongst the cohort operated on by **Azizi and Palaniandy**, seeing that poorer patients benefit the most (the surgery is free in the National University of Malaysia Hospital and with no hidden charges incurred for the use of surgical theatres nor the use of microscopes for microsurgery).

3.0 NOW WE ARE TALKING...

3.1 Spina Bifida And Hydrocephalus

Is [hydrocephalus](#) a type of NTD? Do all people with spina bifida aperta have hydrocephalus ([Dewan & Wellons, 2019](#))? Does hydrocephalus occur during fetal formation, or does it become pronounced after the closure of the open back ([Dewan & Wellons, 2019](#); [Tully & Dobyns, 2014](#))? How many percent of people with open spina bifida in Malaysia have hydrocephalus? Can hydrocephalus be reversed? Does hydrocephalus impair intelligence ([Alimi et al., 2018](#); [Vinck, 2006](#))?

Andy Copp - Professor of Embryology and All Things Neural Tube, who is also perhaps, the person who made the definition of NTD so succinct and without room for the disparity - made appreciation of developmental biology so thoroughly clear that the definition of an NTD is when the neural tube fails to close; therefore, it is impossible to define hydrocephalus as an NTD, but it is instead known to be associated with NTDs ([Copp et al., 2015](#); [Copp et al., 1990](#); [Copp et al., 2003](#)).

3.2 Spina Bifida And Scoliosis

How many percentages of Malaysian patients with spina bifida have scoliosis? Why do they get scoliosis ([Burnei et al., 2015](#); [Cheung et al., 2007](#); [Lowe et al., 2007](#))? Does scoliosis impair intelligence ([Tao et al., 2020](#))? Does scoliosis have an embryological basis ([Burnei et al., 2015](#))? How severe can scoliosis get ([Vialle et al., 2013](#))? What is a gibbus ([Fernbach & Davis, 1986](#))? Why is it necessary to surgically correct scoliosis in a person with spina bifida ([Repko et al., 2008](#))?

I am 46 years old. I was diagnosed with scoliosis when I was 12 during an era when magnetic resonance imaging (MRI) was not in existence in Malaysia. People do not appreciate the difficulties back then regarding surgical correction of scoliosis. I had no idea that Chiari malformation can cause complete paralysis from the neck down if posterior fossa decompression is not performed beforehand ([Rodriguez et al., 2021](#)). I received a mouthful from Dr Jagdeep Singh Nanra about all the dangers of ignoring my worsening tonsillar herniation. It was Jagdeep who stressed to me the person I needed to see was **Associate Professor Muhammad Hisam Muhammad Ariffin**. When I first met **Hisam**, I was gob-smacked. There was absolutely zero hesitation on his part, unlike all the other spine orthopaedic surgeons I have met since time immemorial, including the ones who teach at the same university that I teach. **Hisam** does not know this. I have never mentioned it. **Hisam's** aura is that of a true surgeon. I am a true time-honoured patient-survivor. **Hisam's** face said it all. He knew exactly what needed to be done, and once he looked at just my X-ray, he knew it needed to be done. Not today. But yesterday.

It was a very painful time for me after my scoliosis surgery in every sense of the word painful, although now in retrospect, I have come to the realisation that that pain was necessary. However, it does not negate the mental and psychological anguish I had undergone and what I subjected my poor mother and my closest students to ([Dominy et al., 2021](#)). Having always been the strong one and in control, I needed to be cared for in every sense for the first time. The shock reverberated not only within my home and my lab, it also extended to my collaborators - my fellow scientists, **Azlina** and **Michael**, who literally had to listen to me crying every day for three months. And on the days when I could not reach **Azlina** (who was in Kuala Lumpur at the time) and **Michael** (who was in the United States of America at the time), I reached out to my oldest, dearest scientific collaborator and lab-mate, the late **Mr Meer John Jai Hind Jeffery**. It is ironic really that my Johnny succumbed to COVID-19 when he was the tower of strength for me (I have published more papers with Johnny than with anyone else) having been the one who accompanied me to hospital visits from one neurosurgeon to the next ([Braima et al., 2017](#); [Braima et al., 2013](#); [Jeffery et al., 2012](#); [Mohd Zain et al., 2015](#); [Mokhtar, Braima, et al., 2016](#); [Mokhtar, Sridhar, et al., 2016](#); [Muslimin et al., 2015](#); [Sum et al., 2014](#); [Vellayan et al., 2012](#)). In retrospect, I am quite certain that had I not gotten my spine fixed in 2018, I may have been in far more danger as far as COVID-19 is concerned in this

persistent pandemic. In fact, I had written to **Michael** in May 2018 that I was having problems breathing and could not sleep well and just as soon as I had sent off a text to him that I could not continue as his co-founding editor for Neuroscience Research Notes, seeing that I was not myself at that time; two days later I got admitted for full-blown urinary tract infection, severe headache, diarrhoea, cough and nausea. All of which is gone now. Within three years and five months, not only has sensation returned, but some sensations have also improved. My gastrocnemius, which was non-existent prior to the scoliosis correction, emerged (more than 40 years later – Never say Never). I am stunned, to say the least. Although all that has occurred now was predicted by my Qigong master. I am always in awe of holistic medicine when the best of the West meets the best of the East.

When I wrote this section, I looked back at the texts that were exchanged between **Michael** and myself spanning May until August 2018. Tears rolled down my cheeks immediately. I had gone through so much but had not given myself the time nor the space to allow myself to recognise that, because ALL I want to do now is to WALK. In retrospect, I had most likely saved myself from complete paralysis by choosing not to have the spinal fusion by the implant (instrumentation) done when I was 12. I saved myself by waiting until I was completely comfortable with the choice of surgeons, I weighed all my options and was able to make the best decision for myself. Armed with scientific knowledge, I had spent a lifetime earning the right to learn. With this knowledge, I am now empowering children with spina bifida through Malaysia NTD - knowledge and insight not easily obtained elsewhere, in any part of the world, for there is not anybody else out there like me. The burden and the responsibility are heavy. With great power comes great responsibility – Spiderman.

3.3 Spina Bifida And Mobility

Does lack of mobility impair intelligence ([Tomás et al., 2016](#))? Clinicians call this global developmental delay ([Ashwal & Rust, 2003](#)). I just think this is what happens when children with spina bifida are forced to be even more disabled than what they were originally born with ([Feldman et al., 2008](#)). The child suffers when a spina bifida baby with the aperta type of myelomeningocele is not closed immediately after birth. Physical and chemical perturbation means that even if the lesion site is eventually closed, infection would have been likely to set in and would change the topology of the brain. To think that this does not happen in Malaysia is untrue. A mother exposed to an X-ray scan in the most southern

state of Peninsular Malaysia bore a child with an enormous open lesion on their back. If the back of the child is not closed in a timely manner and if it is not done by a competent neurosurgeon, the child suffers and will be more disabled than what they were originally born with.

Malaysia is extremely lucky to have **Dr Katijahbe Mohd Ali**, a senior clinical physiotherapist who runs a department with their own orthotist, producing the most affordable and quality orthoses in Malaysia – by virtue of the facts that the National University of Malaysia still employs their very own certified prosthetist and orthotist. Great things can be done for a fraction of the price and effective results. It is unjust when many who claim to be experts in the care of spina bifida have such a poor display of return on investment.

Mobility also means that the child with spina bifida should be assessed by the right foot orthopaedician: someone who is eager to help the child, professional, courteous and is of the opinion that the child with spina bifida must be wholly and completely looked after first by the best neurosurgeon in the field. I had never met a foot orthopaedic surgeon in all my 46-years of life on Planet Earth that embodies all the above qualities apart from **Dr Rukmanikanthan Shanmugam**. **Kanthan** is quite frankly, unassuming, very humble and a true professional in every sense of the word. **Kanthan** educated me on the most important objective in managing a child with spina bifida, which is to get the child plantigrade. To achieve this, the child must be managed entirely by the neurosurgeon (if a child requires the necessary untethering of the spinal cord, that should be done first); followed by consistent and effective physiotherapy, and if all the above have been done well, and if contracture of the foot is still present, only then does an orthopaedic surgeon perform any kind of surgery.

Individuals with spina bifida should be encouraged to stand as early as possible at all costs. Spina bifida is a life-long condition. It is a journey which begins in the womb and lasts till death. Children with spina bifida are unique, and to maintain positive brain development, all support and encouragement must be given for the brain to develop in an environment which encourages maximum stimuli. It is thought that the brain of a woman stops developing at the age of 25 and a man's past 25 ([Arain et al., 2013](#)). I have seen children with spina bifida whose physiotherapy regimes were thoroughly neglected, triggering a downward spiral (eyes not being able to focus), then later bounced back

upon being given the correct physiotherapy exercises and being challenged to stand. The eventually walked using orthoses.

3.4 The Psychology of Non-Disabled Individuals Towards Orthoses

One of the most glaring and oft-repeated human behaviours I have witnessed in my 46 years of life and have had the privilege of seeing how people in general who did not pay for the orthoses behave when the orthoses are taken off is telling: I find that people look at the orthoses with disgust and I do not think this is a harsh observation at all. I have seen relatives, domestic helpers, and others in the circle I grew up in, pile up my orthoses in a corner as though they were garbage. I have even had the experience of seeing a family member kick my orthoses in disgust. Now, after three years and five months post-scoliosis surgery and the fact that I do not wear my callipers every day to work, I have also witnessed the lack of respect my domestic helpers have towards these items in a far more glaring manner.

In retrospect, I can understand now more than ever why it is extremely difficult to make an individual with spina bifida compliant with wearing orthoses. It is difficult because even the people surrounding the child (I do not mean the parents per se because they most likely paid for the orthoses, but others who are in the child's social circle) look at the item and make comments about how they are ugly and clunky. Even a look, a non-complimentary look, can seal the deal of how children ultimately perceive themselves. This needs to be said, and this needs to be mentioned clearly and unabashedly because it is the orthoses that prevent contractures in the long run. It is the orthoses that will prevent pressure sores. The orthoses coupled with intensive and consistent physiotherapy will make the child upright and mobile in whatever form or function, given even half the chance. However, the disdain towards these lifelong-required appendages will lead the individual with spina bifida down a life of disability, contractures, or even amputation.

3.5 Does Maternal Diet Contribute to Neural Tube Defects?

The short answer is yes. July 2021 signified the first time Malaysia conceded to having its 1kg flour supply fortified with folic acid ([Dr Ravichandran Jeganathan YouTube video Malaysia Neural Tube Defects Day 2021](#)). However, Malaysia is 20 years behind its neighbour Indonesia in the fortification of folic acid ([Kancherla et al., 2017](#); [Soekirman & Jus' at, 2017](#)).

My laboratory in Universiti Malaya has consistently championed the need to study the Malaysian diet. Our labs are the only ones in the country equipped to study mouse embryonic development. We have found coconut oil and red palm olein to be a rather deleterious choices of cooking oil ([Gunasekaran et al., 2017](#)). The only oil we know positively affects neural tube closure is a particular Black Seed Oil, given a specific fatty acid distribution (unpublished). We know it encourages spinal neural tube closure, but we do not know as of yet if it can rescue murine NTDs. We are testing this hypothesis as I write this. Therefore, the elixir for successful neural tube closure, in my opinion, consists of 1) folic acid if you are having sex, 2) inositol and 3) the specific black seed oil bought from a trusted wholesaler. Buying healthy food in Malaysia requires scientific know-how, an understanding of commerce and, in general, knowing which shops and sellers to trust. A higher cost need not necessarily translate into quality ([Bandy et al., 2019](#)).

4.0 GROWING UP AS A PERSON WITH SPINA BIFIDA IN MALAYSIA

The only thing that mattered to me growing up was to be taken seriously, and the biggest challenge was being thought of as stupid. Malaysia in the 1980s was not a place where one could find children with spina bifida going to school – regular everyday school. Even schools in Britain faced teething problems caused largely by staff unwilling to assist the child with spina bifida ([Welbourn, 1975](#)).

The fear was real, the fear of losing opportunities the moment you present yourself to the world. Worse is living, reliving the hurtful words or decisions made by those in positions of authority that they know better about you ([Wu, 2010](#)) - and these could be teachers, doctors, school bus drivers, distant relatives at family events, even domestic helpers of others: that they have the right to touch you ([Mattei, 2018](#)) to look at where you are different. I remember at an Eid party when I was 10 or 11, a friend of my uncle started talking about the limitations of children with disabilities and my feelings of shame at myself for not being able to stand up for myself in that environment, for the longest time – How could I have noticed how self-censorship as our societal norm had caused irreparable damage to my psyche ([Kelly et al., 2012](#))? Consequently, upon the wonderful and strong tutelage of **Professor Nicholas D.E. Greene** of UCL, I not only acquired the ability to speak in public, but I also no longer felt my voice and my thoughts suppressed by the quaint and inconsequential societal demands for conformity. **Nick** taught me how to

balance my thoughts and my arguments, look at the many sides of any discussion, think on my feet, and remember the pitfalls of being biased. **Nick** did not only make me a better scientist, but he also made me a better person.

The greatest fear in the heart of any school-going student with spina bifida is not to be taken seriously as a bright, academically equal member of their class. It is thus highly interesting that the place where I faced the greatest pushback against the mentally liberated person I felt I was, occurred at the medical faculty where I first worked as a research assistant. The clinicians in specialist training for rehabilitation medicine were the worst. It was there where I witnessed that amongst themselves, even with their peers, they were merciless. If this phenomenon were rooted in intelligence, that would have made it somewhat tolerable to me, but instead, it was driven by an insane desire for this lot to harness as much influence, money, and promotion as possible. Is there an audit of how successful Malaysian rehabilitation consultants are? Is there a method to measure how successful they are as clinicians? They have failed those with spina bifida in Malaysia. **Teoh Jou Yin** was the first person who travelled with me post-scoliosis repair, a true kindred spirit before she moved to London to take up a new teaching job at Brunel University - she happens to be a qualified occupational therapist. We embarked on a long-term project looking at Malaysian spina bifida patients' satisfaction towards services provided by the Consultant Rehabilitation Physicians of Malaysia. We are analysing data and comparing our findings with knowledge obtained from other parts of the world ([Feldman et al., 2008](#)). A current initial search of PubMed for "[dissatisfaction of rehab services](#)" has indicated 272 hits, whereas "[dissatisfaction of rehab doctors](#)" in PubMed has generated 94 hits.

4.1 The Fallacy of the 'Level of Lesion'

To be honest, there are not that many publications out there that I can clearly cite for the 'level of lesion'. Yet this understanding gets repeated as though it were the Gospel and Quranic truth perpetuated by the most extreme right-wing white Conservatives and the most extreme of Muslim terrorists (I can write this because I **AM** a hijab-wearing female Muslim). I speak from experience of the anxiety I feel when I travel to not only the United Kingdom and the United States of America and, surprisingly, to Saudi Arabia. I digress; the only people in the world obsessed with 'level of lesion' in children with spina bifida are apparently Malaysians ([Ong & Sofiah, 2002](#)). Investigate the plethora of paper

publications on the topic and be the judge yourself. Seitzberg et al., ([2007](#)) talks about muscle strength in myelomeningocele, not 'level of lesion'. In fact, it was mentioned that 'level of lesion' cannot be used as a measure of ambulation during the early life of L3-L5. There is hardly any mention of 'level of lesion' made akin to spinal cord injury (not to diminish the importance of SCI) as a means of comparison to spina bifida by the global scientific and medical world apart from (yet again), Malaysians. Why is this, then? That the level of biasness pervades against spina bifida instead of a spirit of learning and understanding by professionals who should be dedicated to understanding one of the most important and potentially disabling of all childhood conditions. I know this because, in 1982, the only book available on spina bifida in the National Library of Malaysia was a single red book detailing and titled 'Spina Bifida in Children'. My mother, I remember, quickly retorted, "Where are the books on Adults with Spina Bifida? Do they all die? Do they not survive their childhood?"

It is interesting to note that we do not even know how many Malaysians have NTDs. There are only two publications on this, and even then, we do not know how many Malaysians have spina bifida ([Boo et al., 2013](#); [Sahmat et al., 2017](#)). We do not know how many Malaysians have had their open spinal cord addressed in a timely manner. It was highly interesting that the panel of reviewers for a Transdisciplinary Research Grant application under Universiti Kebangsaan Malaysia in 2019 were upset that the grant implored an audit type assessment to be done of the management of spina bifida. Why do reviewers who have absolutely zero understanding of NTD feel so threatened that a grant chose to look at service efficiency to the end-user? Is this not the most pertinent in any God-given democracy-driven economics that demand entails supply and that we need to urgently understand the demographics of people with spina bifida in Malaysia?

4.2 The Fallacy of Clean Intermittent Self-Catheterization (CISC)

It is shocking that next to the neurosurgeon, the most important person in the life of an individual with spina bifida would be the urologist. Yet, Malaysia lacks urologists well-versed in the functional bladder (there are only three consultants in Malaysian General Hospitals) and instead, too many urologists in Malaysia go where the money-making machinery lies. Most urologists in Malaysia focus on the prostate and other cancers afflicting the urological system of men ([Conti et al., 2021](#)). This is where issues of children born with a

birth defect who have compromised urinary systems are not addressed in Malaysia. Urologists trained in genitourinary reconstruction are sorely lacking ([Scarberry et al., 2021](#)). This is criminal because we know the dangers of early and continued usage of catheters for CISC. Parents of children with an NTD, especially males, fear the development of strictures ([Martín-Crespo Izquierdo et al., 1995](#); [Scarberry et al., 2021](#)) and other compounding damage to the existing body, including penile injury ([Azar & Shadpour, 2016](#)).

Evidence shows that in individuals with spina bifida, the most important and most fundamental key to long life and health is the ability to void their bladders sufficiently to prevent the flow-back of urine to the kidneys. There are many ways to do this, including the Crede manoeuvre ([Al-Ali et al., 1999](#); [Ewalt & Allen, 1996](#); [Van Kerrebroeck, 1998](#)). I do not understand why there is an obsessive dependence on clean intermittent self-catheterization (CISC) based upon a 1970s method ([Lapides et al., 1972](#)). Finding a way forward means also looking into technology and innovation.

We need to move forward and investigate ways to make things more comfortable for patients. A child with spina bifida should not be regarded as or treated similarly to a person with SCI ([Averbeck & Madersbacher, 2015](#); [Eswara et al., 2018](#); [Flanagan et al., 2013](#)). The child with spina bifida grows up with the disability and learns to manage himself or herself over the years and as such differs completely from the person with SCI not only physiologically but also psychologically ([Averbeck & Madersbacher, 2015](#)).

Publications suggest that the older, the more mature the patient, the better they understand the need to fully void their bladders, resulting in a healthier urological patient ([Wiener et al., 2018](#)). Considering that spina bifida is a condition which begins in the womb, all and every effort should be taken to enable voiding of urine as naturally as possible and for as long as possible. This is also where we have seen considerable success in our cohort of children at Malaysia NTD who have spina bifida and untethered spinal cords, especially those who were untethered before the age of two. These children showed remarkable improvement in their bladder and kidney function ([Kaye et al., 2016](#); [McKibben et al., 2015](#); [Tseng et al., 2008](#)). Voiding the bladder and purging it of urine is necessary and tantamount to the health of the individual with spina bifida, but CISC is not necessarily the only method of achieving that outcome ([Kaye et al., 2016](#)).

Malaysia NTD is exceedingly fortunate to have the services and contribution of **Dr Warren Lo Hwa Loon**.

4.3 The Politicians – Dr M's Methods and How I Grew Up with Them

My biggest crime I think for 30 years at least, is that I grew into becoming an able-ist (having the belief that typical abilities are superior) where I felt that I had a different story because I could walk ([Daalen-Smith, 2006](#)). I thought that the walking I could do through the ages of seven to 17 (I only started using the wheelchair for long distances when I entered Pre-University) was the norm for people with spina bifida when it was in fact the exact opposite. I could walk very quickly and without much exhaustion, from Assunta Secondary School in Jalan Changgai to the MPPJ Library, even on days when I was observing a Ramadhan fast. This was testimony to the expectations I lived up to as a child raised by my very strong mother. I grew up raised by a widowed mother, a disabled grandmother who lost an arm during the Japanese occupation, and two older siblings in an era where Malaysia did not have any provisions for people with disabilities. Considering that Malaysia does not have a dole system, Mahathir Mohammad, the longest-serving Prime Minister of Malaysia (he was Prime Minister throughout my childhood and adult life), made sure all of us became able-ists to a certain extent (<https://www.scribd.com/doc/94784169/Cabaran-Ketujuh-Dalam-Wawasan-2020-lalah-Mewujudkan-Masyarakat-Penyayang>).

In my case, I simply forgot what had happened before the age of seven (other than I was forced to do exercises all the time). I was not given the time to retain memories of being unable to walk, of being unable to carry my arse to the toilet. I did, however retain memories of being excluded based upon others' perceptions of what I could or could not do.

Since returning from London, all I have wanted to do is to build my labs, build my legacy and ensure that my work carries on; but it turned out the first thing I had to decide when I returned home to Malaysia to teach was how much of myself I should reveal. If one had spent decades telling people that one was perfectly all right, normal, and able to participate in all manner of activities like one's peers, how does one now turn around and teach one's students all that is wrong with oneself? It was such a conundrum. Moreover, truth be told, God answered my questions as He often does. Post scoliosis repair, after more than 10 years down the line in Malaysian academia, the answer became apparent: reveal everything in hopes that the truth will set us all

free ([Calloni et al., 2017](#); [Dominy et al., 2021](#); [Mancarella et al., 2019](#); [Mummareddy et al., 2017](#); [Yaltırık et al., 2017](#)). Having fallen into the toilet bowl at Tung Shin hospital soon after the scoliosis repair while I was undergoing acupuncture sessions sent me reeling into fits of laughter, and I found myself no longer refraining from my thoughts or my actions, and I made it abundantly clear to my students, the extension of myself, that this packaging is as it is – take it or leave it. Interestingly, one of my students from my current batch blurted out during a lab meeting that he wished his other supervisor would just be equally straightforward as I had been in all my actions.

5.0 DOES MALAYSIAN LAW PROTECT INDIVIDUALS WITH SPINA BIFIDA?

No, it does not. Never had this been more fully and concisely expressed than the words of **Associate Professor Ramalingam Rajamanickam** ([Malaysia Neural Tube Defects Day Two 2021](#), [ATMA UKM 2020](#)).

5.1 Dealing with Science and Politics of Malaysia

[Malaysia Neural Tube Defects Day 2021](#) was awarded funding by the International Brain Research Organisation (IBRO). It garnered almost 300 online participants that sent us crashing on Day One. I will not be able to do the work that I do without the unfailing support of my scientist friends. It is my scientist friends (Associate Professors Azlina Ahmad Annuar, Michael Ling King Hwa and Cheah Pike See) have supported me for many years – a network of Malaysian neurobiologists and neuroscientists committed to advancing science and the betterment of life. I have argued with them, debated with them, benefitted endlessly from their kindness and generosity, especially in scientific resources, and published with them ([Abdullah et al., 2017](#); [Halim-Fikri et al., 2015](#); [Mansor et al., 2020](#); [Mohd-Zin et al., 2016](#)). They have constantly reminded me to be less of a Mother Teresa and be a little less crazy and perhaps spend a bit more time fulfilling my work KPI. However, they remain loyal in their dedication and commitment to science and – I say this with a lump in my throat, they have been loyal to me through my multiple ward admittance, surgeries over the years, as well as general malaise; and for this, I am eternally grateful (even if I do not show it when I am in the throes of my argumentative self).

I understand the difficulties and anxieties of this condition so very acutely which is why I have built a network among individuals with spina bifida, their families, their care-givers and have tried to a certain extent to get government bodies in Malaysia to have a

vested interests (<http://bfm.my/noraishah-mydin-abdul-aziz-dharmendra-ganesan-spina-bifida> and <https://www.thestar.com.my/metro/focus/2017/06/05/support-group-for-those-with-spina-bifida-researcher-aims-to-bring-individuals-living-with-the-defec/>), none more so than through the IBRO-sponsored Malaysia Neural Tube Defects Day 2021 held on the 7th and 8th of August.

Doing the work we do and enabling it to survive in the most meaningful ways can only happen when fellow colleagues understand and are supportive. Navigating the dangerous channels of Malaysian academia is made meaningful when I am joined by those who persevere to understand me, cutting across the board from the *teh tarik* stalls of Universiti Malaya to the highest office in Chancellory. One such individual is **Aznijar Ahmad Yazid**. I am not sold on those with positions of power and might. I far prefer the company of those who consistently fight for the underdog. Sometimes persevering means having to reach out to other academicians in a multitude of other fields to help us win the war. The history of Malaysian academia and how each nation cultivates the growth of civilisation must be understood from the Malaysian perspective. The fact that the Head of Surgery of one of the most eminent teaching hospitals in Malaysia, **Professor Dr Ong Teng Aik** can give me an honest answer (and I tear up when I say this), that it matters to me growing up as a patient first that I can also get an apology straight from the Head of Surgery. One would hope others in the medical field emulate **Ong Teng Aik** in humility and goodness.

Why is Malaysia NTD not a non-governmental organisation (NGO)? There are a number of reasons why I have kept Malaysia NTD purely as a support group at this juncture and the fact that patients born with spina bifida are being born at an alarming rate, most with the closed version of spina bifida - lipomyelomeningocele. I know first-hand what is tantamount for a child with NTD born and growing up in Malaysia to do well in life. First and foremost, the correct medical care and interventions must take place to enable the child to survive and thrive. A child with NTD must be assessed to determine if they have open or closed spina bifida. If open, immediate surgery with the most competent neurosurgeons who are well-versed in performing closure but who will also advocate for the continuous assessment using state of the art technology; for example, the intra-operative guidance monitoring system ([Zimmermann et al., 2001](#)) must be used. Next comes the cost of performing these surgeries in the 3

top hospitals in Kuala Lumpur: Pusat Perubatan Universiti Malaya, Hospital Canselor Tuanku Mukhriz (PPUKM) and Hospital Kuala Lumpur. **Asrul** keeps on banging on the issues of out-of-pocket expenditure, and this is where data is not easily obtained, apart from what I have gathered through the close relationship I have with the families who are part of Malaysia NTD alongside having spina bifida myself.

5.2 Surgeries and Spina bifida

I often get asked by families if I have a ventriculo-peritoneal shunt. I do not. I was born with lipomyelomeningocele. I have a non-syndromic NTD. The only issues I face have been secondary to the primary issue which is my closed spina bifida. My lesion is high lumbar though, L3 as identified by MRI done in 2005, in England. I learnt how to walk using Knee-Ankle-Foot Orthoses and Axillary Crutches. I was walking, tottering on a hemivertebrae for decades which was elucidated prior to my scoliosis correction before I experienced severe disequilibrium brought upon by tonsillar herniation by virtue of my Chiari malformation. I did not have any issues until I turned 42 years of age. I have an ileal conduit that has lasted 43 years. I have a PhD on the molecular mechanisms of spinal neural tube closure from the University College London. I am an enigma. I know that. Nevertheless, as soon as parents of children with spina bifida aperta meet me, they wonder: "Why doesn't she have a big-sized head? Why can she talk coherently? Why can she ambulate? Why do people listen when she speaks? Why does she command attention?" All these thoughts are racing through their heads. The word '*teruk*' (bad) is much-used in the Malaysian lingua franca. I notice parents in my group oftentimes entertaining, and quite unfairly so, those thoughts of, "why are so-so child not as *teruk* as mine"? And as such, I know that this was coursing through their brains when they asked me the aforementioned question.

On the other extreme end of this debate are the neural tube scientists. I have heard all kinds of nonsense at international meetings. Is NTD one pathophysiological condition or multiple pathophysiological conditions? One disease or many diseases? One gene or combined dosage of multiple genes? Should we do away completely with animal models? Next to the scientists are the surgeons, whose brains are fixated on fixing that ONE thing and that one thing alone, that mice are subservient compared to the sheep when studying an NTD. Suffice to say, I have met all kinds in the world of NTDs.

What is clear to me now: I learnt a lot more, I understood a lot more after I had lost all power and sensation below the waist after my scoliosis repair three years and five months ago. I have now mapped my recovery progress within this time span in my brain. Because I have the honour and privilege to work with so many children with spina bifida, these experiences allow me to see so very clearly and write today that the aetiology of NTDs despite its multitude of phenotypes is governed as single pathophysiology.

I am the same as any of my Malaysia NTD kids. The laws that govern both aperta-type and occulta-type; that govern myelomeningocele and lipomyelomeningocele are the same. All of us need to have our central nervous system encompassing the brain and the spinal cord ensconced safe within a closed system. All of us suffer from tethered cord syndrome and therefore need to be untethered ([Furtado et al., 2020](#); [Gupta et al., 2010](#); [Sarris et al., 2012](#)). Some even reverse neurological deficits ([Gupta et al., 2010](#)). However, untethering of the spinal cord is not meant for the objective of being mobile or more mobile; improvement of mobility is a by-product of correct micro-surgical techniques performed by the most competent of neurosurgeons. Untethering of the spinal cord in our cohort of patients in Malaysia NTD who acted on my advice improved their bladder function, and therefore their kidneys are protected. All of us need to have our bladder evacuated fully. In order to survive and live a meaningful life, we must all be able to do the 5 physiological processes: 1) eat well 2) drink well 3) sleep well 4) defecate well and 5) urinate well.

5.3 Should Doctors Speak Up and When Should Doctors Shut Up

Doctors have so much power. The power of the mind is the most influential to a patient's life. **Zaliha Omar** was the first person who spoke to me as a human being when I was a child in University Hospital. A patient never forgets. It takes a lot to be a good doctor. **Zaliha Omar** is a good doctor. Personally, I do not think one can train a doctor to be a good doctor. A good doctor is someone who is not only highly competent but also "sees" the patient. A good doctor "sees the drama", does not get involved with the drama but influences the drama to achieve best results for his/her patients. When I was introduced to **Associate Professor Azanna Ahmad Kamar** while I was applying for a grant and looking for more paediatricians to join my team, I did not realise I had met **Azanna** many, many moons ago. The grant presentation was short and grant deadlines are usually mind-crushing but I remember immediately being at ease with **Azanna**. I remember when she visited me at

UKMSC after my scoliosis repair, **Azanna** was annoyed at all the external multi branulas hanging from my neck. I wanted to cry. I wanted to scream. **Azanna**, what have I done? Why was I so brave? **Azanna** took one look at my face and she said "Oh Aishah" with all the love she must give to all her patients. **Azanna** is a good doctor. **Azanna** was my senior in secondary school. She knew me when I was a skinny, geeky schoolgirl wearing the most enormous spectacles in a well-known school for producing Miss Malaysia.

What was different this time, at the [Malaysia Neural Tube Defects Day 2021](#) was the collection of speakers. We were a legitimate group that grew together in my effort and desire to procure a research grant that could address many of the searing questions pertaining to NTDs. As much as the Malaysia NTD patient group has benefited from the vast knowledge of so many professionals, these professionals too have benefitted from dealing with someone like me. We in Malaysia NTD advocate for knowledge. Firstly, how many of us are there in Malaysia? Do we survive, and at what age? Do we have a reasonable quality of life? Why were we getting NTDs in Malaysia? Is there something going on with our food and diet?

Doctors should shut up when they do not have all the facts, and they should always leave room for possibilities.

6.0 FUNDING – WHY DO WE NEED CONSISTENT AND RELIABLE RESEARCH FUNDING?

Research grants are difficult to procure, not in Malaysia and certainly not in the United States. So it is with interest that I read that the Eunice Kennedy Shriver National Institute of Child Health and Human Development is now quoting the estimates of spina bifida to be that of 1 in every 3000 births instead of the repeated estimates of NTDs at 1 in 1000 ([University of California San Diego Health, 2020](#)). Global numbers seem to fluctuate depending on which researcher's work is being cited. Having worked and interacted with researchers in the field in both the United Kingdom and the United States of America ([Copp et al., 2013](#); [Wallingford et al., 2013](#)) and having spina bifida myself alongside actively working on spina bifida research, I find that it is becoming increasingly relevant for each nation to come up with their own number of those afflicted with neural tube defect and this fact came to light as many from developing nations seem to be citing Mohd-Zin et al., (2017) if not Sahmat et al., (2017). This highlights that Malaysian researchers, meaning my group, are paving the way forward to show the

importance for local NTD researchers of each nation to become involved and invested, which includes: (Zoghi et al., (2021)-Iran, Việt (2021)-Vietnam, Royo-Salvador et al., (2020)-Spain, Rahmad et al., (2021)- Indonesia, and Ortiz-Cruz et al., (2021) - Mexico).

6.1 My Legacy

This is why scientists need continuous and reliable research funding. To keep the postgraduate students alive and able to do good science at all hours of the day and night in order to find answers to questions which can help society. I love science but I am not able to fit into the mould of the 'Malaysian researcher'. I do not feel myself bound to the restrictions governing output as I am far more interested in knowing that the work done in my labs can liberate entire generations of Malaysians from the consequences of spina bifida. The freedom I beseech is one which comes in the form of not having to worry about being different instead of constantly being in a state of battle. I have now trained an army of students from various fields to battle in my name. Not only are they battling for me, but they are also battling for my Malaysia NTD kids with spina bifida. The list is long. But each and every one of them holds a place in my heart; they are (past and present): NorLinda Abdullah, Mohammed Rafid Shaker, Kamil Ali Obeid Braima, Mustakiza Muslimin, Aida Syafinaz Mokhtar, Renuka Gunasekaran, Adibah Sahmat, **Siti Waheeda Mohd Zin @ Zain, Nisheljeet Singh Khalsa and Nivrenjeet Singh Khalsa**. I truly hate it when an academican is only assessed on the numbers of students they produce, not the quality of what we are sending out there into the real world.

6.2 The Annoying Scientists

Both clinicians and scientists in the field of NTDs have neglected to thoroughly understand the aetiology and mechanism of spina bifida occulta compared to spina bifida aperta, the open-lesioned NTD ([Mohd-Zin et al., 2017](#); [Padmanabhan, 2006](#)). Recent papers have indicated that the surface ectoderm plays a much bigger role than previously thought. As far back as 1995, Jacobson & Moury have shown that closure could not be achieved without the presence of at least some non-neural ectodermal cells in the vertebrate axolotl. Recent studies by Abdul-Aziz et al. (2009), Camerer et al. (2010), Pyrgaki et al. (2010), and Szabo et al. (2009) all suggest that the surface ectoderm is indeed required for successful closure of the neural tube - both in the cranial and spinal regions of the developing neural tube in comparison to the long-held belief that it is primarily the neural tissue of the neural tube (the neuroepithelium) that is required for successful closure ([Jacobson &](#)

[Moury, 1995](#); [Moury & Schoenwolf, 1995](#)). Even my much-debated claim that all things "neural tube" are led by an asymmetrical tissue has somewhat reached wider acceptance ([Maniou et al., 2021](#)).

6.3 Genetics vs Environment

Does it hold water when doctors tell couples with children with spina bifida in Malaysia not to have any more children when published literature on the Malaysian scenario on termination of pregnancy is not in existence ([Khitamy, 2013](#); [Trudell & Odibo, 2014](#))? I have never seen a single case of a mother having consecutive babies with NTDs in Malaysia. What we do see are uncles and aunts born with anencephaly with a niece or a nephew suffering from spina bifida. This is of course anecdotal evidence that if we had received a Long-Term Research Grant (LRGS), we would be able to answer all the relevant questions pertinent to Malaysia. I had chosen **Professor Thong Meow-Keong** to be the leader for all my LRGS applications. I have known **MK Thong** since I was in my school pinafore. His consultation room was always next to my paediatrician. Clinic was always conducted at the same time at Polyclinic E, and I always registered myself when I attended the clinic, memorising my number 348288 and spouting those numbers ridiculously fast just to irritate the nurses. As a schoolgirl back then, what I witnessed was the Grade-A kindness that **MK Thong** bestowed upon his patients and their worried parents. I had never witnessed a medical doctor opening the door for his or her patient, not in the 1980s, definitely not in Malaysia. Having **MK Thong** onboard Malaysia NTD does not only define the contribution that genetics play a role in neural tube closure as it does in all medical conditions but more importantly, it underlines the lack of concerted studies in truly understanding Malaysian NTD genetics. But what holds true irrespective of global location is that the syndromic neural tube defect would have a far greater genetic contribution than its non-syndromic counterpart ([Mohd-Zin et al., 2017](#)). And as such, we should come to the conclusion that by scientific deduction, most cases of spina bifida around the world, including in Malaysia, are triggered by environmental events affecting the developing embryo. What we also see and are documenting is that almost every Malaysian mother who gave birth to a baby with spina bifida reported circumstances that were challenging to their pregnancies ranging from difficulties in maintaining the pregnancy (at least five women in our cohort took Clomid) ([Auffret et al., 2019](#)), to suffering a severe asthma attack during the early days of the affected pregnancy ([Lin et al., 2012](#)), and took painkillers such Ponstan and Naproxen during the time

their baby with spina bifida was conceived ([Esposito et al., 2021](#); [Oakeshott & Hunt, 1991](#)). Furthermore, a majority had gestational diabetes ([Dell'Edera et al., 2017](#); [Hay, 2011](#)). This further reinforces the knowledge that the environment is a pivotal factor in determining the occurrence of a neural tube defect during gestation. Furthermore, paternal contributions to NTDs have also been thoroughly neglected by the scientific community ([Naufal et al., 2009](#); [Schacter et al., 1984](#)).

The issue of haploinsufficiency being the principal reason behind the prevalence of NTDs in the human population is telling ([Johnson et al., 2019](#); [Mohd-Zin et al., 2017](#)). The evidence abounds ([Sakurai et al., 2010](#)). The last count of mouse NTDs puts us at more than 250 mouse models ([Harris and Juriloff, 2010](#)). You can knock out a gene fully in the mouse embryo, but you cannot do that in a human fetus. What I mean is that we as human beings with spina bifida populating planet Earth most likely possess the orthologue genes of the least penetrant amongst that of the murine spina bifida genes; thus, we are unable to find a single spina bifida gene that can be used to screen the global human population. This brings me back to the idea that any gene we possess as humans, if it is expressed in the developing brain and the developing spinal cord during neural tube closure, can be perturbed and cause spina bifida if (1) there exists too little or too much expression of that gene, and (2) an environmental trigger causes the conceptus to be affected when neural tube closure is occurring in the womb.

I have had couples approach me for advice and input when they have been made aware that they are expecting a baby with NTD. That they use me to decide whether they would want to keep their "bun in the oven" alive honestly angers me. Still, I will show them the difficulties unabashedly, and people will make pretty awful parents when they cannot cope even with watching me stow away my electric wheelchair into my SUV. I feel the same about my fellow academics. I am a patient first, and I am a person with spina bifida first before I am a woman, before I am a scientist, before I am an academician, before everything else. DO NOT EXPECT ME TO PUT THE NEEDS OF INDIVIDUALS WITH SPINA BIFIDA AFTER OTHER CONSIDERATIONS. This applies to the argumentative parents who want to do things their own way after approaching me for help and assistance. I have a clear plan based on the clear insight that nobody else possesses, so I make it abundantly clear that Malaysia NTD is about improving the quality of life of individuals with spina bifida. It does not care, nor does it take into account the needs nor the desires

of the parent, other than the only desire to see their child improve in terms of health and abilities.

7.0 LITIGATION AND THE WORLD OF NEURAL TUBE DEFECTS IN MALAYSIA

Recently, a landmark finding against a Harley Street doctor brought the issue of litigation straight to the world's doorstep. A Queen's Counsel found the doctor of Evie Toombes's mother guilty of neglecting to give the correct advice of folic acid supplementation to their patient, who then gave birth to a daughter having spina bifida (<https://www.thetimes.co.uk/article/spina-bifida-showjumper-evie-toombes-sues-mother-s-gp-over-her-birth-rl66gfmf6>). It is not without great pride that I would like to mention here the case in which my team and I helped a Malaysian woman settle out of court for a sum of RM 1 million when she was prescribed four months' worth of an anti-folate medication ([Abdullah et al., 2018](#)).

8.0 COVID-19 AND THE AWARENESS IT HAS BROUGHT TO OUR DOORSTEP IN MALAYSIA

One of the most apparent and jarring things that I have noted during this pandemic is the depths of laziness of most academics, especially clinical academics in Malaysia. Many truly do not keep up with their reading of scientific literature, and I feel embarrassed when they call themselves Professors ([Van Noorden & Singh Chawla, 2019](#)). However, the pandemic has brought with it DEATH, and this is something that cannot be ignored. So, in the past, if academicians and clinicians in Malaysia claimed things cannot be done and cannot be improved for fetuses born with birth defects and, in particular, NTDs; my opinion is that they are just NOT READING ENOUGH. The relatively recent outbreak of microcephaly brought upon the knowledge that a virus, Zika, can contribute to this neurological problem. This has stoked interest again in infectious diseases possibly causing NTDs. This is timely considering the recent outbreak of microorganisms potentially causing birth defects ([Devakumar et al., 2018](#)), with **Andy Copp** as an author on the cited paper. Through our extensive work with the NTD community in Malaysia, my team and I have discovered cases in our cohort of children with spina bifida whose mothers suffered infectious diseases such as dengue fever and toxoplasmosis while pregnant with the said babies. It is with this observation that I implore that research into birth defects in Malaysia simply cannot be ignored, and more research funding is needed.

9.0 MOVING FORWARD

I have the honour of being the only person with spina bifida to have done a PhD on spina bifida. It also puts me in an uncomfortable situation of seeing scientific data which are less than whole but taken like Gospel / Quranic truth. When I look at some of the data on the Quality of Life of individuals with spina bifida written by Malaysian and global researchers, I cannot but scoff at what I see as the non-disabled community's need to feel comfortable over an uncomfortable topic.

Religion and dependence on God on the other hand apparently is seen as weaknesses and inability to argue the different sides coherently, fairly and without bias. Truth be told, anything which involves the dispensation of bias requires a lot of hard work. Such is science that any reliance or dependence on a higher being is met with undue scrutiny and even disgust by the scientific community. But we persevere and do what is best for the NTD community of Malaysia. Faith, being the number one tenet of the Malaysian constitution and is about the one thing most Malaysians can agree on, cannot simply be discounted to give the families an emotional reprieve, hope, and understanding. In fact, in my experience, it is the only thing that keeps these families going. Whatever the outcome, I am here, and I am watching (and I also write), so best to arm yourselves (those who are lazy clinicians and lazy scientists) if you are publishing data on spina bifida in Malaysia. I am watching, I am scientifically and medically literate, and I am armed with a fastidious nature.

10.0 THE URGENCY

Birth defects, in particular, spina bifida are not diminishing in Malaysia. The numbers are not becoming lesser; the numbers are becoming more. [One in five Malaysians has diabetes](#). We have zero data on what the Malaysian diet does to the womb of the sexually active Malaysian woman. We should be more scared, especially in the current climate of Malaysian politics. To ignore this article is to ignore your wives, girlfriends, and daughters and trample on the memories of your mother, your grandmother, and great-grandmother.

Social Security Organisation (SOCSO) Malaysia cites us ([Tam et al., 2020](#)), yet the Malaysian Ministry of Education/ Higher Education have turned us down for two Long-term Research Grant Scheme (LRGS), two Prototype Research Grant Scheme (PRGS), three Trans-disciplinary Research Grant Scheme (TRGS), five Fundamental Research Grant Scheme (FRGS) applications. Furthermore, we had applied for the [Newton Ungku Omar grant](#) organised by British Council

Malaysia in 2016, amounting to GBP 363,551, which could have addressed the enigma of blood folate levels of Malaysian women once and for all. We were shortlisted but ultimately lost to the Institute of Medical Research cancer group because apparently, they had a novel idea, and we did not. I am at a loss as to the priorities of my beloved country in its efforts to understand and further prevent this significant birth defect.

All the names mentioned in this article and highlighted in bold are a part of Malaysia Neural Tube Defects and have consented to the contents associated with their names. I am indebted to all of them. In this life and the next.

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