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Dear Sir/Madam

Thank you for the opportunity to submit this letter to the inquiry into concussions in contact sport. I am Professor Karen Barlow, the director of the Complex Concussion Program within the statewide Queensland Paediatric Rehabilitation Service (QPRS). I am a neurologist and brain injury specialist who has been treating children with persistent post-concussion symptoms for 25 years. Also, as a clinician researcher I have demonstrated that children with concussion and mild traumatic brain injury (mTBI) have a poorer outcome than previously recognized and the neurobiological underpinnings of these persistent symptoms. Through cohort studies and clinical trials, I have demonstrated how these outcomes can be improved and translated many of the strategies into clinical practice. As such, I am recognized as an international expert in post-concussion syndrome (PCS; #20 in the world, #2 in Australia, *Expertscape*). I am a member of the International TBI Research Consortium and Australian Connectivity TBI consortium and contribute to the International Consensus Statement on Concussion in Sport. I would like to take this opportunity to highlight some of the gaps in our knowledge and provision of care for children with persistent symptoms after concussion.

**A public health issue, the size of the problem of concussion in children and youth is huge.** Concussion sits within the spectrum of mild traumatic brain injury (mTBI). It is increasingly recognized that the term "mild" TBI here is misleading as between 24% and 53% of people with mTBI/concussion have long-term symptoms and significant functional impairments one year after injury<sup>1-3</sup>, and also because there are growing concerns about the role of mTBI in future dementia<sup>4</sup>. The impacts of concussion are greater in children as the brain injury is occurring during a period of rapid developmental and psychosocial change. 20% of all children and youth have at least one mTBI<sup>5</sup>; with 70% of these occurring during sport. 7% of children have had three or more concussions<sup>1</sup>. These concussions are more likely to occur in contact sports. As 12% of children play Australian Football and/or Rugby which carry the highest concussion incidence rates of any sport, this number is worrisome unless we make it safer to play<sup>6</sup>. So why don't we take concussions more seriously?

#### *What happens after the hit – short and long term effects in children*

Despite the media attention, there is a lack of public awareness of the consequences of concussion in Queensland and in Australia. Although many people know that "head knocks" occur, few are aware that about 50% of children have symptoms that last at least a month or that 14 -33% of children have poor outcomes with symptoms lasting 3 months or longer<sup>1</sup>. These *post-concussion symptoms* include any or all of the following:

- **significant pain due to headaches.** These post-traumatic headaches occur all day every day in 50% of paediatric cases<sup>7</sup>. This is a very high pain burden for which more treatments are required.<sup>8</sup>
- **difficulty concentrating, remembering, and paying attention** in class. This is at a time when, as children, they are supposed to be learning lots of new information and concussion often results in poor attendance at school<sup>9</sup>.
- **balance problems, dizziness and visual disturbances** which are not only distressing, but often predispose them to further injury<sup>10, 11</sup>.
- **poor sleep and mood disturbances.** A lack of sleep makes everything more difficult. Mood disturbances often last the longest and occur due to not only the injury but also due to the child's anxiety about their lack of

recovery, their sense of loss because they can no longer participate in activities they enjoy, and the decreased contact with their friends<sup>12, 13</sup>.

### *Biology of Post-concussion Symptoms*

Over the last 10 years we now have evidence to show the longer-term effects of concussion on a child's brain and are beginning to understand why some people do not recover quickly. My research has used brain imaging techniques to show how post-concussion symptoms are associated with changes in the brain. These changes include the altered ability of brain regions to communicate with each other<sup>14</sup>, changes in the blood flow to the brain<sup>15</sup>, and alterations in the way the brain uses energy<sup>16, 17</sup>. Increasing our knowledge about brain recovery after concussion helps us design and investigate treatments to improve outcomes. Importantly, research indicates that the child's brain is often still recovering even when symptoms have resolved<sup>9, 15</sup>. Unlike fractures or wounds, this injury cannot be seen on routine tests. One reason why this is often referred to as a "silent epidemic". **This means that a child's return to activities that place them at risk of further injury needs to be carefully monitored by people with expertise in the area and that families need support during this journey.** Indeed, we still don't really know how long it takes for the brain to fully recover and further research like this is needed to help us understand the best and safest way to get children back to school and play.

The impact of post-concussion symptoms on a child/youth and their family is very significant. It leads to a marked decrease in the child's quality of life<sup>18</sup>, poorer attendance and performance at school, and decreased participation in everyday activities. **As these children look normal and talk normally, their symptoms are unfortunately often dismissed or minimized, and they don't get the help and support they need.**

### *Supporting children and families during the journey to recovery*

Every year, around 2500 children with concussion attend the Queensland Children's Hospital (QCH) Emergency Department (ED) alone. Most children are discharged home. Unfortunately, between 40-60% of patients with mTBI leave EDs without education or discharge instructions and without a clear follow-up plan. This is important as clinical outcomes can be improved by educating patients about their diagnosis, the possible early symptoms and their natural history, and by providing early follow-up<sup>19-21</sup>. Given the pressures on hospital resources, it is not possible to follow every child in hospital and we rely on families attending their General Practitioner. Despite our efforts and guidelines<sup>22</sup>, patients and families are still not sure how to get help, especially if their local doctor has not received training in concussion<sup>23</sup> or if their symptoms are dismissed<sup>24</sup>. This leads to a **potential gap in care for the children whose symptoms persist but it is also an opportunity for improvement.**

A "lack of services" and an "inability to find help" for their symptoms was the most common statement from the consumer advisory group for the Australia and New Zealand Guidelines for Management of Concussion and mTBI in Adults and Children Development project (MRFF grant, CIA Barlow).

*We need pathways to access concussion care.* With the QCH Emergency Department and Qld General Practitioners, Dr. Barlow and QPRS have developed a clinical pathway to provide support for every child with concussion seen through QCH in a time and cost-effective way ([www.kidsconcussion.com.au](http://www.kidsconcussion.com.au)). We have also worked with Education Queensland, to advise on similar management pathways for concussions occurring at school or during sport/rugby carnivals and these will be implemented this year. We have shared our learnings with the [Brain and Spinal Cord Injury Project](#) (BaSCI) and Queensland Excellence Health Pathways so that adults with concussion will also know how to access to care across Qld (<https://spotonhealth.communityhealthpathways.org/246668.htm>). Through BaSCI, some concussion clinics for adults have been funded but this project did not include funds for children. We would like to fully implement this clinical pathway for children and take them to the broader Queensland community in the future but this would require extra healthcare resources.

### *More publicly funded multidisciplinary complex concussion clinics to treat long-term effects*

For many people, follow-up with their GP is sufficient to ensure their road to speedy recovery when these guidelines are followed. The management of children and adults with persistent post-concussion symptoms, however, is often complex<sup>25</sup>. **It is best practice that adults and children with persistent symptoms (PPCS) are managed by a**



**multidisciplinary team of clinicians with experience in managing PPCS<sup>22, 26, 27</sup>.** This team includes a doctor, nurses, physiotherapist, neuropsychologist and occupational therapist<sup>21</sup>.

- Nurses contact families before clinic, so that families get help within a week or two of referral, providing medical advice and organising early review if there are “red flags”
- Medical doctors consider alternative diagnoses, suggests treatment (pharmacological and non-pharmacological) and look for confounding factors complicating the child’s recovery<sup>25</sup> as well as modifiable/treatable risk factors for poor outcome (e.g. lack of exercise, chronic pain, mood problems and poor sleep)<sup>28</sup>.
- Physiotherapists, as per 2020 physiotherapy guidelines<sup>29</sup>, assess cervical musculoskeletal, vestibular, and motor/coordination impairments and provide advice on exercise intolerance and prescribe graded exercise programs
- Neuropsychologists have a vital role<sup>30</sup>. They assess the cognitive issues and liaise with school and family to help with “return to learn” strategies in a developmental framework. They conduct assessments and early management of mood and behavioural problems and referring on to treatment providers in the community as required.

However, there is a significant gap in our knowledge about the best treatments for persistent post-concussion symptoms<sup>31</sup> and the potential for childhood concussion (especially repeated) to lead or predispose that person to early onset dementia<sup>28</sup>. It is critical that more research and clinical trials are performed to meet this unmet need and I encourage that this is embedded into new service delivery models.

**Multidisciplinary concussion services are unfortunately scarce** in Qld and Australia and practically non-existent in rural areas. The Complex Concussion Program in QPRS sees children with PPCS across Qld. However, the demand is great. An audit of our service revealed that every child seen required 64 hours of further service delivery to address their needs. We need more resources in order to meet both the high demand and significant morbidity as well as clinics or telehealth clinics to reach children in North Queensland and rural areas.

*Why publicly-funded?* Unfortunately, sometimes private providers offer services in concussion without expertise and experience in this area – especially in children. Sometimes specialists not familiar with paediatric concussion disregard the influence of development, age-specific norms, and developmental conditions on their findings<sup>32</sup>. This often leads to unnecessary stress and concern for families. Further, many families do not have resources to pay the high private sectors fees creating an inequality in health care provision.

#### *Prevention is key*

The old adage that “prevention is better than cure” is certainly true in concussion. Yet in addition to primary prevention, secondary and tertiary (preventing further concussion in those at risk) prevention strategies are also key considerations to improve outcomes. Before coming to Australia, I was part of the University of Calgary Concussion Research Program. Here, investigators demonstrated that the removal of body checking in childhood hockey (PeeWee, Bantham), **decreased the number of concussions by 60%** without compromising their skill development<sup>33, 34</sup>. This led to sport policy changes across Canada and the National Hockey League. Other primary prevention strategies include wearing helmets in skiing, and potentially mouth guards in hockey (not in rugby). Research should be encouraged to investigate strategies to prevent concussion in junior rugby and Australian football as this has great potential to lead to a major decrease in morbidity due to concussion in youth while allowing people to still enjoy the game. Secondary prevention strategies likely to decrease the risk of prolonged symptoms include

- enforcing “when in doubt sit them out”<sup>35</sup> emphasizing that playing through it is not cool. It is key that sporting bodies definitively get on board with this.
- encouraging early return to light activities and exercise and avoiding too much screen time<sup>36</sup>. More strategies like this are needed.

**In summary**, I greatly welcome this inquiry. Innumerable children sustain concussion during contact sport. There are many opportunities to both prevent concussion and decrease their impact in children by improving the support and health service provision they need.

Yours sincerely,

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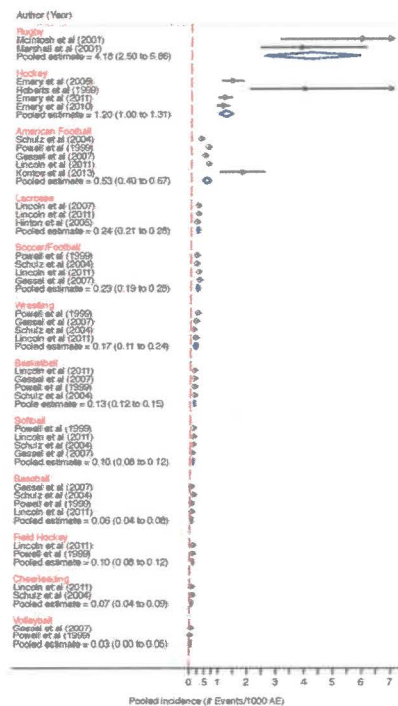


Figure: From Pfister et al., Rugby has the highest incidence of concussion in youth sport.

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