

ABI Trajectories Study Newsletter #2



Trajectories and Consequences: Long-term follow-up of children and youth and their families after Acquired Brain Injury (ABI)

ABI Trajectories Study Team:

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ABI Trajectories Study is sponsored by:



The ABI Trajectories Study Team would like to express our gratitude to all of you who took the time and effort to provide us with invaluable information. We are now starting the **THIRD** study year and we will continue the follow-up with 92 participating families (and teachers as well)! Each family is on a different schedule, depending on when the child's ABI occurred. 42 families have already finished the 5th year post injury/illness assessments, while others just completed the 4th year assessments. Also, 25 of you have done the neuropsychological testing with us! We thank you all very much for your continued participation!

NEUROPSYCHOLOGICAL TESTING, EH?

As we have announced in the last newsletter, when it comes to the time for the 5th year post injury/illness assessment, a neuropsychological testing session will be scheduled for you. We are trying to find out how ABI affects the children and families in the long term, and neuropsychological function is one area that we are particularly interested in. For this important component of the study, we welcome two new members to our ABI Trajectories Study Team, **Dr. Erin Warriner** and **Dr. Beth Adams**. Erin is our Supervising Neuropsychologist (practice in clinical psychology and neuropsychology). Beth is our psychometrist, and she will be administering the tests during the neuropsychological testing session.



So, what is this neuropsychological testing session?

Basically, it is an evaluation of brain functions, and how they have been affected by ABI. Its purpose is to understand more about the brain and how the injury/illness affects behaviours and thinking ability.

One may also wonder what the neuropsychological testing session involves...

A wide range of tests will be administered by Beth to evaluate areas such as attention, memory, language abilities, etc.. Nothing intrusive is involved! There are no needles or scary medical equipment.

Then what? What should one expect to get after the testing is done?

Beth will score all of the tests. Together with Erin, they will prepare a summary report with your personal scores being compared to a normative group of individuals of the same chronological age. From this individualized summary report, you will learn more about each test and how to interpret your scores. Although the data was collected as part of a research protocol that was not intended to be a formal or comprehensive neuropsychological assessment, you may choose to share the information with school or medical personnel as you wish.

ANOTHER NEW STUDY TEAM MEMBER...

We are very happy to announce that we have another biostatistician, [Liqin Xu](#), onboard. Liqin has a Master of Science degree (Statistics) from McMaster University.



She will work closely with our principal investigators, Steve Hanna and Carol DeMatteo, to analyze the information that all of you have kindly shared with us! Using statistical techniques, they will enable the study team to better answer the research questions that we set to investigate since the very beginning (i.e., the long-term effects of ABI).

"MY CHILD DOESN'T HAVE A BRAIN INJURY, HE ONLY HAS A CONCUSSION."

At some points in time, you may have heard someone making the above statement; or maybe, you have said so yourself. What is brain injury? What is concussion? Are we talking about two different things or are they the same? And sometimes people feel it's not important to follow children who only have "mild" injuries. But there is a problem sometimes figuring out what truly is a mild injury.

Presently, at least eight different scales for concussion grades exist with no universal agreement. The grading systems represent clinical expertise not research evidence, and all, except the recent Canadian Pediatric Association (CPS) definition of concussion, have focused on adults, not children.

Some of our study team members, Carol DeMatteo, Steve Hanna, Mary Law, Louise Scott, Bill Mahoney, Anne Newman, and Liqin Xu, together with Dr. Rob Hollenberg have recently completed a study funded by Ontario Neurotrauma Foundation (ONF), with hopes to establish valid criteria for classification of Mild Traumatic Brain Injury (MTBI) in Children.

This MTBI study completed a secondary analysis using the ABI Transitions dataset. Various advanced statistical techniques were used to help answer the research question. The results indicated a clinical diagnostic dilemma between concussion and MTBI. Some of the study conclusions were:

- Concussion and MTBI are the same. Concussion syndrome is the same as MTBI symptoms. If you have a concussion, then you do have a brain injury.
- MTBI is rarely used as a diagnosis, and concussion is often labeled without consistent guidelines.

The MTBI study team made some recommendations based on their findings:

- Parents should be told that their child has a brain injury even when it's mild.
- Consistent guidelines for diagnosis and intervention for MTBI/Concussion must be implemented.

For more information, please visit ONF website at <http://www.onf.org/knowledge/OutcomeResults.aspx>

YOU STILL HAVE A CHANCE TO WIN AN IPOD®^{1,2}

We would like you to know how much we appreciate your time and effort. Last year, we announced the launch of the iPod®^{1,2} lottery draw annual event. Of course, we kept our words. Our first lucky winner³ has already enjoyed the prize since the beginning of this year, congratulations!

For the rest of you, there are still TWO more iPod®^{1,2} to be won⁴. Simply return your completed booklet or finish the online questionnaire, you will earn yourself a chance to WIN an iPod®^{1,2}!

So, don't let the booklet sit on your kitchen counter for too long, or if you choose the online version, logon to our website NOW!



You may be the next iPod®^{1,2} winner!



¹ Retail value and actual prize depends on the latest product from the iPod® family at the time of draw

² iPod® is a registered trademark of Apple Computer, Inc., registered in the U.S. and other countries. Apple is not a participant or sponsor of this promotion.

³ For privacy and confidentiality reasons, we cannot release the identification information of the winner.

⁴ One prize per winner throughout the course of the study

YOU CAN ALSO COMPLETE THE QUESTIONS ONLINE

Some of you have already tried to complete the questionnaires online this year with great successes. We are glad to learn that you have found the process to be user-friendly and that our website is easy to navigate through. For those who haven't tried the online version and would like to do so for the next assessment, please let the research coordinator, Chia-Yu, know when she calls your family next time.

For those who prefer to complete the questionnaires in the booklet format, of course, this option is still fine! So, you will be able to choose the format that is most convenient for you and your family!



A HELMET WORD GAME¹

Can yuo raed tihs?

Bciylce hmleets porectt yuor bairn form dmagae in a carsh and can svae yuor lfie. In 2003-2004, there wree 815 haed injuries due to cylicng that reuqried hopsitliazation in Cnaada². You need a hmelet eevn for srhot reids aaround yuor nighorboohd, or for rdiing to shoocl. Smoe plcaes hvae lwas taht rquerie you to waer a hemlet. Raecrs lkie Lnace Amrsrtng waer teihr heemlts too.

Why can you sitll raed tihs msseage?

Aoccdrnig to rscheearch, it deosn't mttar in waht oredr the ltteers in a wrod are, the olny iprmoetnt tihng is taht the frist and lsat ltteer be at the rghit plcae. The rset can be a total mses and you can sitll raed it. Tihis is bcuseae the huamn mnid deos not raed ervey lteter by istlef, but the wrod as a wlohe. In fcat, teh fstaer you raed teh esaier it is! Amzanig, huh?

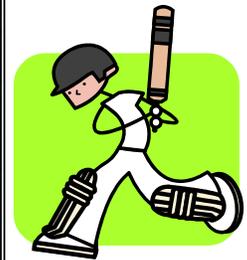
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This is a fun demonstration of an interesting fact. Spammers learned it long ago as they looked for words to get around email filters. But **spelling is still important!** Notice how much *easier* and *faster* it is to read this paragraph than what is above. People may judge your communications--and you--by the content and the accuracy of your spelling and grammar. If your spelling is wrong, they will be distracted and may not pay attention to what you are trying to say. **So be careful with your spelling and it will pay off!**

Sources:

¹ The Helmet Word Game Template is copyrighted by Bicycle Helmet Safety Institute (<http://www.helmets.org/index.htm>) and is used with permission.

² The Canadian statistics cited in this Helmet Word Game is from the Canadian Institute for Health Information August 2006 publication, Head Injuries in Canada: A Decade of Change (1994-1995 to 2003-2004)



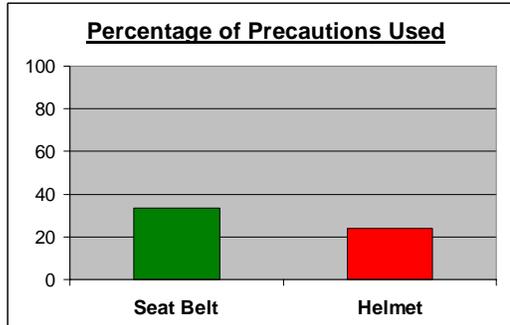
For more information about "Helmet use", you may check out the "Got Wheels? Get a Helmet!" fact sheet from Safe Kids Canada at <http://www.sickkids.ca/SKCFForParents/custom/GotWheelsGetAHelmetColour.pdf>



BE SAFE! USE PRECAUTIONS!

We have analyzed some of the data collected from the ABI Transitions Study, and have found some alarming results that we would like to draw your attention to.

Among those injured in motor vehicle accidents as passengers or drivers, only 32% of them were wearing seat belts! Even more striking is that of those injured in bicycle-related accidents, only 24% of them were wearing helmets!



**Be sure to protect yourself and your loved ones!
Always remember to use helmets and seat belts!**

ANY FEEDBACK ABOUT THE STUDY?

We strongly encourage you and your family to continue sharing your comments with us throughout the course of the study. Some of you have already done so by calling us or writing down your thoughts on the comment section in the study booklet. We always like to know what you and your family think about participating in this study!

ANY CHANGES IN YOUR CONTACT INFORMATION?

If you have moved, changed your phone number, or plan to do so in the near future, please keep us posted! We would like to make sure we have your most current contact information so we can keep you and your family involved in the study. More importantly, we can send you and your family the findings from the study at the end!

You can let us know about any changes in your contact information by sending an e-mail (linchia@mcmaster.ca), by calling Chia-Yu (905-525-9140, ext. 26842), or write to us by regular mail:



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WHAT'S NEXT?

We will continue to contact you and your family on a yearly basis. For the future assessments, you still have choices between the paper booklet and the online version. When it comes to the time for the 5th year post injury/illness assessment, in addition to the questionnaires, we will also try to schedule a neuropsychological testing session for you and your family which will take place at our centre.

RESOURCE



Find out more about *CanChild's* research and resources related children and youth with brain injury...

<http://www.canchild.ca/Default.aspx?tabid=504&SubIndId=67#SubZoom>



Kidsafe Connection has some great information on safety and injury prevention, such as bicycle safety, pedestrian safety, and sport safety.

<http://www.capitalhealth.ca/YourHealth/Campaigns/Kidsafe/default.htm>



Toronto ABI Network has developed an online **Family Resource Guide** which includes useful information in areas such as "Family Recovery" and "Back to School".

<http://www.abinetwork.ca/familyresourceguide/home.htm>



Neuroscience for kids is a resourceful website for children, parents, and teacher who would like to learn more about the nervous system. It has lots of fun stuff, such as interactive games and more...

www.bvmschool.on.ca/home.html

