

ABI Trajectories Study Newsletter #1



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

ABI Trajectories Study Team:

Carol DeMatteo, Steve Hanna,
Mary Law, Louise Scott,
Bill Mahoney, Anne Newman,
and Chia-Yu Lin



The ABI Trajectories Team would like to say a HUGE thank-you for your continued participation in this follow-up study. We would like to express our appreciation to the parents, children, youth, young adults, and teachers who took the time and effort to provide us with invaluable and extremely useful information. Your participation will contribute to increasing our knowledge about the long-term prognosis and help us to provide better care for children and families who experience brain injury in the future!

ABI Trajectories Study is sponsored by:



WHY ARE WE DOING THIS STUDY?

After an ABI, children and youth and their families may experience changes in many areas of their lives. These may include physical and mental health, ways of thinking, behaviour, social and family life, self-concept, and economic circumstances. Recovery from ABI varies a great deal among children and youth. Our understanding of the recovery process among young people is complicated because this recovery is happening at the same time as changes that occur naturally as part of typical development. We also know very little about the growing brain's ability to heal itself. Many doctors and researchers working in this area assume that children who seem to have mild injuries early on will have no problems later. In fact, we don't really know about the medium and long-term consequences of mild ABI. It is possible that some of these children and their families will have difficulties in the future, in spite of apparently complete recovery in the weeks immediately following injury.

In this study, we are trying to:

- To find out how ABI affects the children and families in the long term (i.e., over 5 to 7 years). We are particularly interested in quality of life and neuropsychological function*
- To examine how these factors change as youth move from adolescence to being young adults.
- To learn how to identify which children and adolescents will require more intensive intervention and follow-up.

** A research-focused neuropsychological testing session will be scheduled when the participant is five years post injury. We are interested in learning changes after ABI in areas of attention, memory, and others.*

HOW ARE WE DOING SO FAR?

This study began in December 2005 when we started to contact families who kindly participated in the Transitions Study a few years earlier. Now that the study has been up and running for almost a year, we are delighted to learn that many families continue to be a part of this follow-up study! Every family is on a different schedule, depending on when the injury occurred.

Unfortunately, we were unable to reach some families from the Transitions Study, because the contact information was not up to date. But from those whom we had contacted, the response rate has been great! We are excited to announce that we have 98 families participating in the study! For the young people who are still in school, we also have their teachers' involvement as well.

We would like to take this opportunity to share with you briefly about some of our interesting study findings.

- Among children, adolescents, and young adults with ABI in this study, 63.3% of them are male while the other 36.7% are female (Figure 1).
- **Motor Vehicle Accidents** account for almost HALF of the injuries (Figure 2).
- Among those injured in motor vehicle accidents as passengers or drivers, **only 40%** of them were wearing **seatbelts!**
- Even more striking is that of those injured in bicycling accidents, **only 27%** of them were wearing **helmets!**

Figure 1: Gender of the Participating Children, Adolescents, and Young Adults with ABI

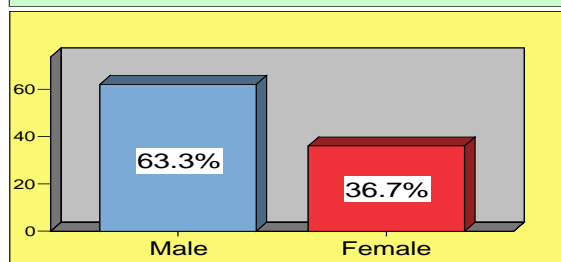
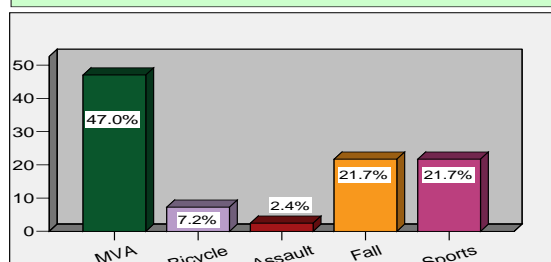


Figure 2: Mechanism of Injury



YOU CAN WIN AN IPOD®^{1,2}!

We would like you to know how much we appreciate your time and effort. Each year, when we receive your completed booklet, you earn yourself a chance to WIN an iPod®^{1,2}!

This lottery draw will take place throughout the course of the study, which means one iPod®^{1,2} will be drawn once a year for THREE consecutive years on December 31st! Winners will be notified by phone.

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.

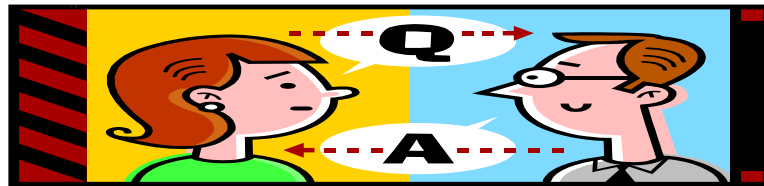
³ One prize per winner throughout the course of the study

☺ YOU CAN NOW COMPLETE THE QUESTIONS ONLINE ☺

We have learned a lot from you, not just about ABI-related information, but also how to facilitate the whole research process. Some of you gave us a really great idea - you said **WE SHOULD MAKE THE QUESTIONS AVAILABLE ONLINE** so that more children, adolescents and young adults would be more motivated to participate!



For your next yearly study booklet, if you would like to complete it online, please let the research coordinator, Chia-Yu, know when she calls next time or simply send Chia-Yu an e-mail with "ABI Trajectories Study" and YOUR NAME in the subject line. You will then be given detailed instructions, a username and password to help you answer questions online. The information will be sent to you by E-mail. Please make sure to have Chia-Yu's e-mail address (linchia@mcmaster.ca) on your safe list!



FREQUENTLY ASKED QUESTIONS

YES, we are listening! Many of you are asking us some very good questions. Here are a few examples.

Q. Why do we have to complete the same questions over and over?

A. We know that it may be frustrating to answer the same questions each year, especially with the amount of questions that we have been asking you! One reason we ask you to do this is to make sure we collect the same information each time. This allows us to look at possible changes, if any, in you and your family.

You may feel that the information you share with us does not change over time, we are interested in that as well. Every family is unique, some have many changes and some don't. This will be important to know. When we report our findings at the end of the study, we need to show that we have collected our data in a consistent manner. If we don't do it this way, someone may argue that there may be other things that impacted our findings and that our results may not be accurate.

Q. What can I learn about myself/my child from this study?

A. As we summarize the findings, we want to make sure that you and your family have a chance to learn from the study. However, since the study is done for research purposes, rather than clinical assessments, we cannot provide feedback on specific information about you or your family. Rather, we can report more generally about the whole participating group of children, adolescents, young adults and their families. We will share what we learn with you and your family by sending the Study Newsletters!

That being said, we would still like to hear from you about what you would like to know when the results come out and how the findings can be most helpful to you!

**Special thanks to Patricia Hurley who kindly shares her expertise and knowledge in preparation for this FAQ section.

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. Thank you! We always like to know what you and your family think about participating in this study!

RESOURCE:



CanChild has a new website now, please come and check it out!

www.canchild.ca



ThinkFirst National Injury Prevention Foundation has some fun stuff on safety for kids, adolescents and young adults.

www.thinkfirst.org/home.asp



Ontario Brain Injury Association has many useful resources that you and your family may find useful!

www.obia.on.ca



Bloorview School Authority's website has information on its ABI program (which aims to meet the needs of students with ABI at the elementary and secondary school level), and it also has potential bursary opportunities

www.bvmschool.on.ca/home.html



Caring for Kids is a website developed by Canadian Paediatric Society to provide valuable information on children's health and well-being. Here is the information regarding sport-related concussion for parents, coaches and trainers:

<http://www.caringforkids.cps.ca/keepingkidssafe/Concussion.htm>

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 by sending an e-mail (linchia@mcmaster.ca), by calling Chia-Yu (905-525-9140, ext. 26842), or write to us by regular mail:

ABI Trajectories Study
c/o Chia-Yu Lin
CanChild, IAHS Room 408-F
McMaster University
1400 Main Street West
Hamilton, Ontario, L8S 1C7

WHAT'S NEXT?

We will continue to contact you and your family on a yearly basis. For the future assessments, you can choose between traditional paper booklet and the new online version. When it comes to the time for the 5th year assessment (since injury/illness), in addition to the study booklet, we will also try to schedule a neuropsychological testing session for you and your family which will take place at our centre.

Remember to wear
your **HELMET!!**

