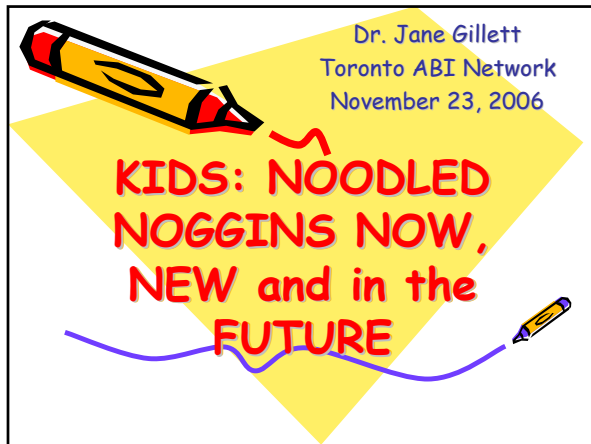


Dr. Jane Gillett  
Toronto ABI Network  
November 23, 2006

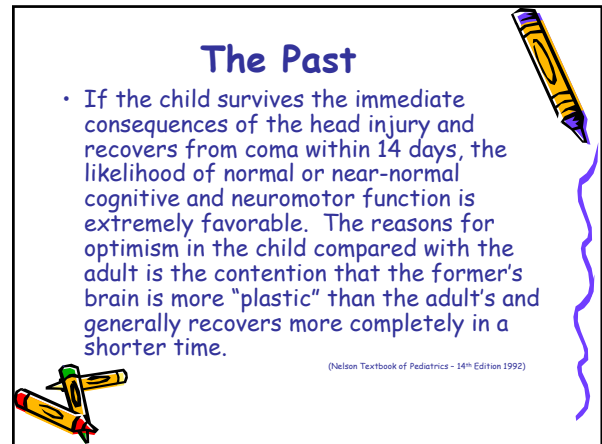


**KIDS: NOODLED  
NOGGINS NOW,  
NEW and in the  
FUTURE**

### The Past


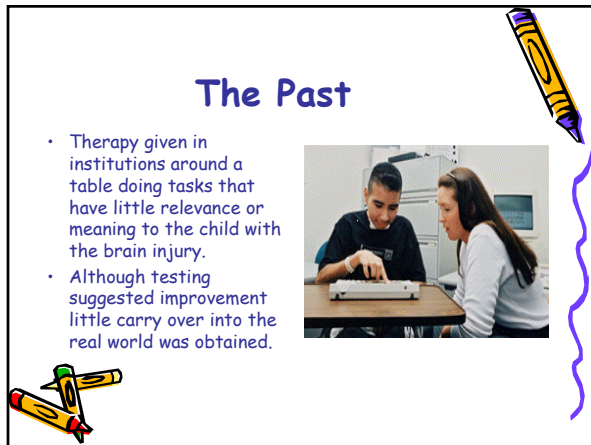
- If the child survives the immediate consequences of the head injury and recovers from coma within 14 days, the likelihood of normal or near-normal cognitive and neuromotor function is extremely favorable. The reasons for optimism in the child compared with the adult is the contention that the former's brain is more "plastic" than the adult's and generally recovers more completely in a shorter time.

(Nelson Textbook of Pediatrics - 14th Edition 1992)



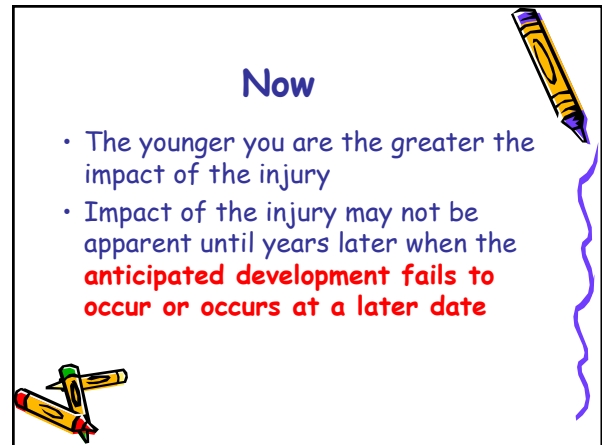
### The Past

- Therapy given in institutions around a table doing tasks that have little relevance or meaning to the child with the brain injury.
- Although testing suggested improvement little carry over into the real world was obtained.

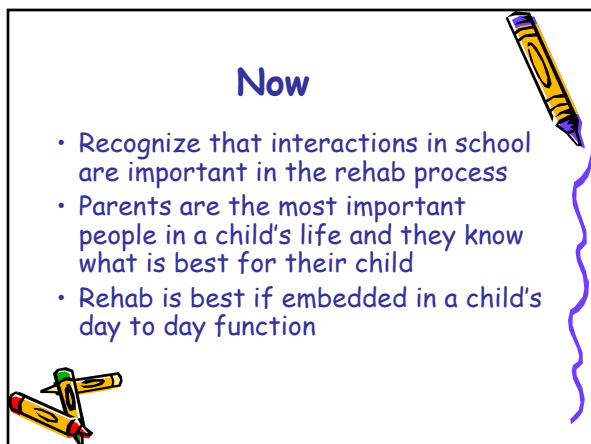
### Now

- The younger you are the greater the impact of the injury
- Impact of the injury may not be apparent until years later when the **anticipated development fails to occur or occurs at a later date**



### Now

- Recognize that interactions in school are important in the rehab process
- Parents are the most important people in a child's life and they know what is best for their child
- Rehab is best if embedded in a child's day to day function



### Now

- Programs have been developed that address the multiple issues that arise
  - Development
  - School
  - Driving
  - Drugs/Alcohol
  - Sports
  - Puberty
  - Emotions
  - Independence
  - Self Individuation
  - Friends



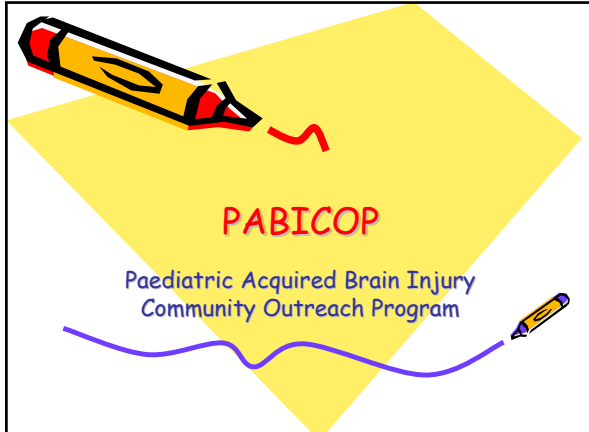
**Now**

- PABICOP
- Bloorview MacMillan
- Kingston
- Ottawa
- Hamilton
- Windsor



**PABICOP**

Paediatric Acquired Brain Injury  
Community Outreach Program




**Paediatric Acquired Brain Injury  
Community Outreach Program**

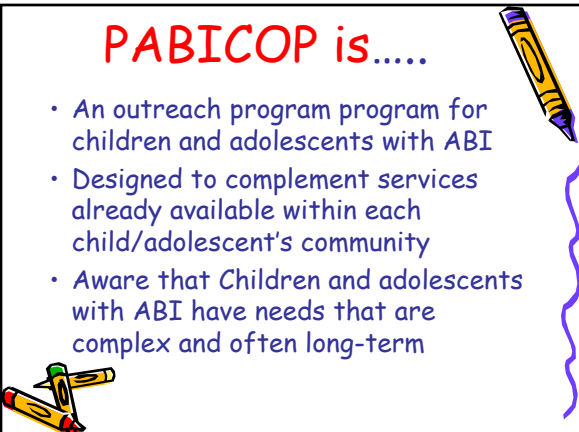
An Innovative Program to assist  
families and their communities in  
providing care for children and youth  
with ABI

- Believes in:
  - Continuity
  - Empowerment
  - Accessibility
  - Knowledge
  - Integration
  - Advocacy



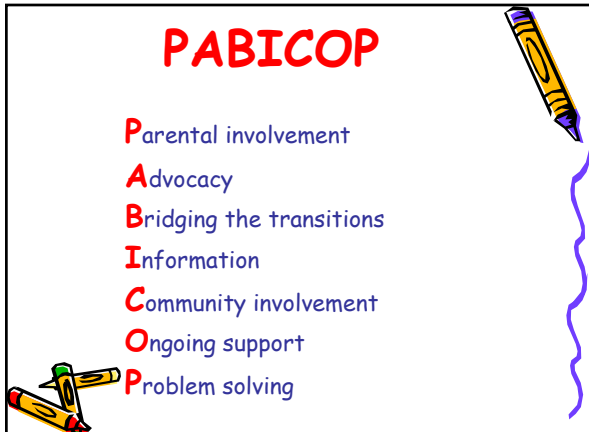
**PABICOP is.....**

- An outreach program program for children and adolescents with ABI
- Designed to complement services already available within each child/adolescent's community
- Aware that Children and adolescents with ABI have needs that are complex and often long-term




**PABICOP**

**P**arental involvement  
**A**dvocacy  
**B**ridging the transitions  
**I**nformation  
**C**ommunity involvement  
**O**ngoing support  
**P**roblem solving




## New ... but very old

- **Talk to the child** and ask him/her what he/she wants to do and what helps

## Barry





Hi, my name is Barry Phelan and I am 20 years old and live in Wingham Ontario. When I was 8 I was involved in a car bicycle accident outside my home.

I suffered severe brain injuries, required brain surgery and was in a coma for weeks.

When I woke up I could not walk, talk, eat or do anything for myself. I had to learn to do everything all over again.

The worst for me was not being able to speak. I understood everything that was said to me, but could not use my voice. I had to rely on picture boards and pointing. No matter how hard I tried, I could not say anything.






It is so hard to concentrate for hours each day in Rehab. I know now that it was worth it, but I remember feeling so exhausted that I could not even think when therapy was over.

I was so determined to be myself again. I decided to work my hardest to gain back everything that I had lost. I worked for me and for my family. I wanted to see them smile again, they were so sad and worried about me. I also wanted to get back to my life again in school with my friends.

There were times I was so frustrated and angry. I worked so hard but did not feel I was improving, especially in speech. I know I was young but I often felt that everybody talked to my parents about me but they forgot to explain things to me. I was not stupid, I just could not say what I was feeling.



I went to counseling for a long time and it helped me to realize that I would have to make a new life for myself, no one else could do it, I had to create a life where I would be happy. People who have a brain injury need counseling, do not wait until they are really depressed, it should be a part of Rehab.

I love sports and before my accident I was really good at baseball and hockey. I tried to play those sports again after my accident but was just not coordinated enough. I tried curling, karate and soccer. I was involved in track and field events and found that I just loved to run. I joined the High School team and the Ontario Cerebral Palsy Sports Association and started to train hard everyday.

Joining the Ontario Cerebral Palsy Sports Association has given me a purpose in life. I was classified, which means I compete with athletes with similar abilities. I compete in the 100 and 200 meter track events. It has taken me 8 years to meet the Canadian standards to represent Canada at the World Championships in Amsterdam in September 2006 .



Going back to school was a lot harder than I expected. In the beginning everyone was nice to me and really helpful, but it did not take long before my friends realized I was not the same Barry as before. No matter how hard I tried I could not fit in. I had no one to play with or hang out with and I became really depressed.



I have traveled throughout the province, the country, the states, Argentina, and Europe representing my sport. I am currently ranked 5<sup>th</sup> in the world within my classification.

When I started High School I was in essential courses, however, I would not be able to get my High School Diploma unless I took applied level courses. So I repeated subjects over again so that I was able with support to graduate with my high school diploma. I have also completed a diploma in health and fitness and hope to continue my education. We know that childhood obesity is a major health concern; I would like to be able to assist physical education teachers to design programs for children within the school system to promote physical fitness.

If you believe and have the determination to succeed, you can achieve any goals or dreams that you want, but you need the support of your family. You need them to talk to, believe in you and accept you for the person that you have become not the person you were before. It takes hard work and perseverance to be the best that you can be and it really helps to have a sense of humor.

I don't know what I could have done with my life if I did not have a brain injury; however, I believe that I can live my life the way I want to, and be happy and successful. I would like to thank all of the people that have believed in me in so many ways especially Dr. Jane Gillett who was with me throughout my journey. I hope that by sharing my story I can show you that a meaningful recovery from a brain injury is not only possible but has helped me to be the person that you see today.


## The Themes

- Talk to me
- Listen to me
- Accept ME
- Counsel me
- I get lonely and I am lonely
- Help me find something that I want to do and has meaning for me
- Have FAITH in ME and allow me to have faith too




## New ... but very old

- **PARENTS** or the primary caregivers are the **MOST IMPORTANT** people in the child/youth's life.
- **PARENTS KNOW** what is **BEST** for their child and for their **FAMILY**.



## New ... but very old

 **LISTEN**  
 **LISTEN**  
 **LISTEN**  
 **LISTEN**  
 **LISTEN**



## Liz



One of the greatest nightmares for any parent is that one of their children gets injured or ill. From the day your child is born you fight tooth and nail to protect them from harm. However sometimes it happens and you have to learn to **parent** in a totally different way.



On a sunny Sept. day in 1993, Barry was stuck by a car while riding his bicycle outside our home. He sustained massive brain injuries and was not expected to live. I would like to read from a journal entry I wrote at the time, as it helps to show you where he has come from.

It is 2 a.m. and the CT scan is complete. We haven't seen Barry since he left Wingham 8-hrs ago. Could it be that long and yet it seems like it was just minutes ago. We can't sit stand or talk, wrapped in our world of frantic caring and helplessness. Thoughts enter and leave at a faster pace than the traffic on the 401.

If only he had been wearing his a helmet, if he had just waited a couple of moments for his brother. **If, if,** if such a small word that carries so much weight. Waiting must be the single most exhausting exercise. Time is at a standstill, hangs like a noose around your neck giving your brain the opportunity to imagine and believe the worst possible case scenarios.

Finally the Surgical team arrive, they plan to operate immediately. They offer no hope, no assurance, just a promise they will do their best. A pregnant pause, too long a silence, 'Have you given any thought to organ donation'. We are hoping that it will not come to that, but best to be prepared.



Prepared for what, not having our son anymore, of losing part of ourselves. Every single atom of my being froze at that moment. I could not form an answer, even though my medical background cried out to take whatever part of my son that could help someone else. I couldn't say it, because speaking aloud would be giving up hope that he might survive. You don't have to answer right away; we will be in touch as soon as the surgery is over, why don't you get some rest.

I wanted to scream, you have just asked for our sons organs and get some rest in the same sentence, do you have any idea what that feels like?? Instead I just say Please do your very best, he is very special and we do not want to lose him. The Neurosurgeon hesitates and says he will let us know as soon as the surgery is over. He will need to elevate the skull fracture and remove the damaged brain'.

I can't believe it was almost 13 years ago. Sometimes it feels like yesterday but it has also been a long hard battle, one that was well worth fighting for.

We were involved with case managers, psychologists, behavioural therapists, Psychiatrists, computer specialist, school integration officers, social workers just to name a few.



We were involved with case managers, psychologists, behavioural therapists, Psychiatrists, computer specialist, school integration officers, social workers just to name a few.

We were analysed, scrutinized monitored and measured, we had an impact analysis done and entered the world of future care costing. Our entire family life was put under a microscope and we had to share our home with strangers. If we agreed with their recommendations we were compliant, if we did not agree we were a dysfunctional family.

We met wonderful people, leaders in their profession who knew how to listen to the unique challenges we faced accessing services in rural Ontario. They understood that often it was not possible for us to make an early morning appointment in London or Toronto in the winter months.

However there were several professionals who either did not understand acquired brain injury, or who had no passion for their work and would not listen to what we as parents had to say.

I learned to play the game to access whatever service Barry required and an occasion would have received an academy award for my performance.



My message was clear, we as parents are the full time caregivers and while we respect your knowledge we will do what is best for our son. The family is the most important part of the care team.

The school system posed many challenges also, by far the single biggest change agent within the education system are parents. Involved parent's equal motivated children. Don't assume that teachers and guidance counsellors even special education teachers understand the needs of a student with an acquired brain injury. Question decisions made for your child and above all advocate ensuring that Acquired Brain Injury deserves the same recognition as other disabilities and entitle the student to an educational assistant.

One of the hardest areas we faced was watching Barry try to fit in. He went from being the kid who **picked** the team to being the kid that no one wanted on his team. He loved sports prior to his accident and really wanted to get involved again. We enrolled Barry in every sport available in our area from Hockey to Baseball. Curling to Karate.

It was while playing soccer that we noticed he sure could run. He didn't look pretty but he was fast.



Getting involved in Paralympics has been the best thing for our family. A happy child keeps a family happy, a miserable child affects everyone. Barry has been determined and has been **inspired by athletes within the sports world who have achieved despite overcoming extreme physical challenges**. He works out at least 5 times a week in the Gym and on the track. He has travelled both Nationally and Internationally, representing Cerebral Palsy. He has achieved his ranking through hard work, determination and Sport Politics. Above all he has found his niche and he is happy.

We will be there in Amsterdam cheering him on if he makes the final selection and pray that he makes it to Beijing to represent Canada at the Olympics in 2008.

Back on that fateful day in Sept. 1993 we prayed that if Barry lived he would be happy and have a meaningful life.

It is an accepted fact that we actually use a very small part of our brain; Barry is proof that with the right support and training dormant areas of the brain can take over. He is also proof that recovery is ongoing and not limited to the first two years post injury.



We are a normal family and do not assume we have all the answers, we just want all of our children to maximize their potential and are prepared to support them to achieve their goals.

His motivation to achieve, his great big smile, his sense of humour and his charismatic ways have exceeded all of our expectations.

Families need your support, in the areas of speciality services, Rehab and best practice. Professionals need to talk to each other to avoid the family repeating their story over and over again. We need a Health Information System that allows Professionals to share information. Above all we need a Health Care System that allows the family to be an intrinsic part of the Health Care Team and does not just pay lip service to family involvement. We cannot allow a two tired Health System for those who have insurance dollars and those who do not. Finally, prepare parents for what lies ahead when their children are brain injured, forewarned is forearmed.

I want to thank everyone who helped us on our journey. I hope that by sharing our experience we can motivate you, and inspire great progress in the field of Neuro trauma Research. A small investment now can lead to a valuable member of society in the future.



## New

- Restraint therapy
  - Physically restricting the good arm in stroke makes the paralyzed arm work again and fMRI shows increased activity around the usual region after the intervention where little was seen before

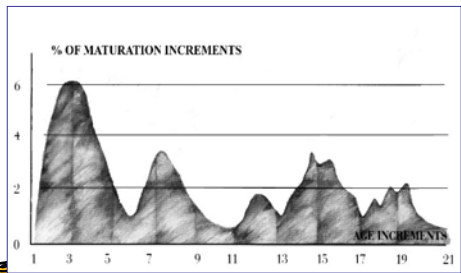


## New

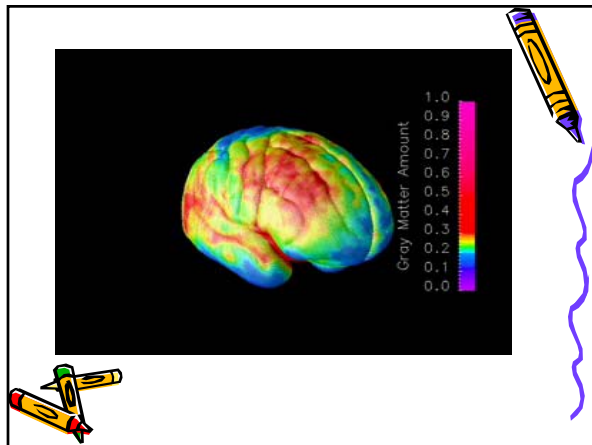
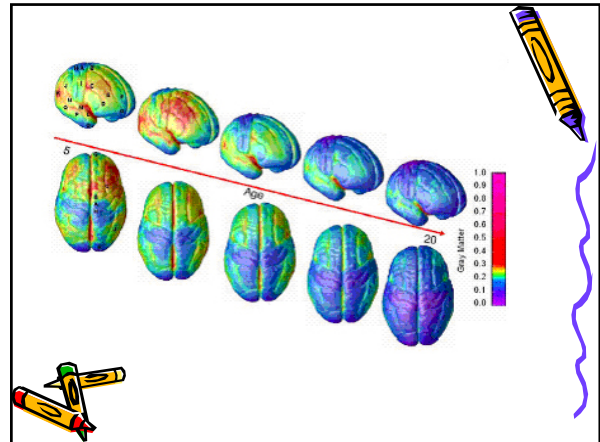
- Brain Maturation and Planned Cell Death
  - There are several periods throughout childhood and adolescence in which the brain undergoes a wave of cell growth and connections. Immediately after the wave there is a wave of "planned apoptosis" to prune unnecessary connections and increase the efficiency of the ones that remain. If pruning fails to occur - autistic like features appear and if too much pruning occurs - then schizophrenic features occur.



## % of Maturation Increments- All Brain Regions



Savage, Ronald C. The Child's Brain: injury and development. L & A Publishing, Wake Forest, NC. 2000



## Future

- Brain injury prevention
  - Province wide "Stay on your Feet"
  - Province wide Shaken Baby Prevention
  - Province wide helmet use for sports and for cycling for all ages
  - Vaccines for the prevention of the encephalitides, meningitides including Lyme disease and West Nile virus

## Future

- Ameliorating the impact within the first 48 hrs
  - Progesterone and brain protection
  - Melatonin in the newborn
  - Erythropoietin like agents that provide tissue protection
  - Aquaporin 4 receptor blockers that prevent astrocytes from producing cytotoxic edema and cell death

## Future

- Improving recovery with drugs (old and new) selected by your gender and genes
  - Leukotriene inhibitors chosen according to your phenotype
  - Apo-lipoprotein stabilizers (especially for apo-lipoprotein B4)

## The Far Future

- One day in the not too distant future brain surgery will be a thing of the past.
- Technology will surpass anything we know now and this is how we will fix a brain injury.

