



WHAT WAS THE OMG STUDY ABOUT?

When told that their child has cerebral palsy, many parents first ask: 'How serious is it?' and 'Will our child walk?' Until now these important questions have been difficult to answer because we didn't have evidence of all the facts. Through a joint venture with the Children's Treatment Centres in Ontario, *CanChild* Centre for Childhood Disability Research at McMaster University is in a unique position to study issues like this. The Ontario Motor Growth (OMG) Study - which you and your family may have been part of - has given us more information to answer parents' questions. This report outlines what we have learned so far and what we plan to do in the future.

HOW DID WE START?

It is clear that cerebral palsy affects the control a person has over body movements - sometimes the effects are small and sometimes they are large. In the past, service providers have talked about the amount of movement problems in terms of 'mild', 'moderate' or 'severe' cerebral palsy. As far as we know no one has ever been able to agree on what these words actually mean! We found this situation frustrating, so we developed a system to define the range of gross motor function of children with cerebral palsy more clearly. This way, service providers and families all over the world will have a consistent and common language when we talk about these issues.

With the help of service providers from many Ontario children's centres, we created the Gross Motor Function Classification System, or GMFCS (we've included a copy for you in this package). For the first time, the GMFCS gives us a standard way to describe differences in the gross motor function of children with cerebral palsy. The GMFCS describes five 'levels' of motor function. Each level is different from the other levels in ways that, we believe, are important for daily life. Within each level there are descriptions of motor abilities at different ages. The system can be used easily by service providers (such as therapists and doctors), and many parents have also told us they find it useful. We know that when different people classify a child's motor abilities using

the GMFCS, they very often agree exactly about which level applies to that child. We also have learned that most children tend to stay in the same GMFCS level over time. This is important because it means that we can begin to understand early in a child's life what motor skills the child is likely to achieve as they get older.

Since we first made the GMFCS available to people around the world, it has been translated into at least six languages, and is now regularly mentioned when people write about children with cerebral palsy. We have also put together a training videotape that teaches service providers about using the GMFCS. We are continuing to do more work to improve the GMFCS. For example, we are hoping to expand the GMFCS to include what we learn about the abilities of teenagers with cerebral palsy in our next study.

WHAT DID WE DO TO LEARN ABOUT A CHILD'S OUTLOOK FOR MOTOR FUNCTION?

In some of our early research about motor development in children with cerebral palsy (in the late 1980's) we were able to show that there were differences in motor development according to whether the children had what was then still being called 'mild', 'moderate' or 'severe' cerebral palsy. We know, however, that the best way to understand how children grow, or how their abilities change over time, is to measure the same children many times over several years. We can then link these measurements together to produce a line (usually a curved line) that, in effect, 'connects the dots'. When this same process is done with a large number of children, and we use a more accurate system to classify function (our GMFCS), it is possible to create five separate 'motor growth' curves. These curves are similar to the growth charts (describing height and weight) used by pediatricians and family doctors to decide whether babies and children are growing as expected.

In order to try to make our findings useful for all children with cerebral palsy we needed to make sure that the children who participated in the OMG Study were typical of children with cerebral palsy across Ontario. To do this we worked with 18 of the

children's treatment centres and one additional therapy program. We found out that there were 2108 children in Ontario with cerebral palsy under the age of 11 in 1996 when the study began. We used random selection (which is like picking a number out of a hat) until we ended up with 682 families of children with cerebral palsy who wanted to participate in the research. At the start of the study these children ranged in age from 1 to 13 years old and had a wide range of motor abilities. **Table 1 below** shows the ages and the GMFCS levels of the 657 children with cerebral palsy who had enough study assessments to be included in the 'motor growth' curves we've created.

As you may remember, in the OMG Study we wanted to measure each child's gross motor function every 6-12 months (less often as children got older). The tool we used to measure motor activities was the Gross Motor Function Measure (GMFM), another measure we developed many years ago that is now used around the world. The GMFM was designed to assess whether, and how much, children change their motor abilities over time. It looks at what children do in lying and rolling, crawling and kneeling, sitting, standing, and walking, running and jumping. It does not look at how well children do these things, although this is another area of on-going research by our group.

Therapists who did the GMFM assessments were from centres that are part of the Ontario Association of Children's Rehabilitation Services (OACRS). They were all trained to use the GMFM measure correctly and were retested every year to be sure they continued to use the GMFM in the same way. They were also the same people who made classifications

using the GMFCS at each visit.

WHAT HAVE WE LEARNED SO FAR?

A total of 2,781 GMFM assessments were done between August 1996 and February 2001! We then carried out a 'join the dots' statistical analysis that links all the information about each individual child, and then links the different children in each GMFCS level. The resulting 'motor growth' curves are shown in **Figure 1 on page 5**.

What we see is that in each GMFCS level there is a general pattern of improvement in gross motor development over time that is specific for that level, and is different from each other level. From these graphs we know the:

- average amount of change children show on the GMFM over time.
- 'age-90' is different for each level (the age-90 is the age when an average child reaches 90% of their expected motor development in that GMFCS level).

You can also see that, at the top right corner of each graph there are two dotted lines, above and below the end of the labeled motor growth curve. These lines tell us that 50% of the children in that GMFCS level will have a GMFM score within that range by the time they are 7 or 8 years old. This also means that in any GMFCS level some children will score higher and some lower than others. The GMFCS level therefore tells us a lot (but not everything) about how much or how well a child's motor development may happen. Factors such as a child's interests, motivation, health and other aspects of development will also make a difference in a child's motor development.

Table 1: Age and GMFCS level for 657 children included in the 'motor growth' curves

Age of children ↓	Gross Motor Function Classification (GMFCS)					Total (657 children) ↓
	Level I (183 children) ↓	Level II (80 children) ↓	Level III (122 children) ↓	Level IV (137 children) ↓	Level V (135 children) ↓	
1-2 years	16	13	13	12	14	68
3-4 years	47	20	22	30	22	141
5-6 years	30	15	30	30	36	141
7-8 years	36	14	27	29	32	138
9-10 years	36	18	20	31	26	131
More than 10 years	18	0	10	5	5	38

WHAT DOES ALL THIS WORK MEAN FOR FAMILIES?

Lets get back to why we began this work in the first place – to be able to provide families with answers to those two important questions. The work we have done – with the help of hundreds of Ontario parents like you – has provided us with a good starting point for answering these questions.

1) How serious is our child's cerebral palsy?

The GMFCS makes it possible to give advice to parents about the extent of their child's motor difficulties, and thus to answer this first question.

2) Will our child walk? With the 'motor growth' curves we can now also begin to make a prediction about the pattern of gross motor development of children in the same GMFCS level, and have a pretty good idea about what to expect for this second question.

It is extremely important for parents, therapists, program managers, funders, and other decision makers not to assume that, at a time when the curves appear to level off, further therapy is unhelpful. We all need to continue to make every effort to find ways to increase children's independence in 'activities' so they can do as much as possible. We also need to work to ensure that children's movement is as efficient and effective as possible even when things are not achieved easily. It is equally important to make efforts to promote 'participation' of children with disabilities, so that they can be part of the community at large and use their motor and other abilities to best advantage for social development and the development of their own interests.

AND...There are some other important issues to keep in mind about this work.

First, the results of the OMG Study are based on the therapies and treatments that are currently used for children with cerebral palsy. We believe that services in Ontario are up-to-date and well provided so we are confident that what we have learned represents the way children with cerebral palsy are likely to develop using the therapies we presently have available to us. As new treatments become available it is likely that these curves may change to show better or faster development. When that happens it may be necessary to change these curves.

Second, the GMFM looks at gross motor function in

terms of the activities that allow children to become independent in their whole body movement. However, the GMFM assessment tells us nothing about the quality of motor control (smoothness, efficiency, ease of movement) children use to do things. We know from other studies that this is a part of motor development that seems to come along later in childhood. The 'motor growth' curves also tell us nothing about how children use their motor function in daily life, for play and activity at home/at school/in the community.

Third, the GMFM was set up to assess motor function tasks achieved independently by the child. The GMFM does not look at how augmentative and technical interventions such as aids, orthoses or the use of powered mobility may increase day-to-day independence. What has been observed in the OMG Study shows us, on average, the motor activity that children with cerebral palsy can be expected to show without any help.

WHERE DO WE GO FROM HERE?

Several activities are happening now at the *CanChild* research centre:

We still have a great deal to learn about the motor development and function of adolescents with cerebral palsy. As you may already have heard, *CanChild* has received funding from the Canadian Institutes of Health Research to do a follow up study with teenagers for the next 5 years. This study is called the Adolescent Study of Quality of life, Mobility and Exercise or the "ASQME Study" (pronounced ASK ME). The ASQME Study will allow us to continue by looking at teens with cerebral palsy and hopefully to extend our curves to the end of the teenage years. We also want to know more about the things that teens with cerebral palsy do in functional activities, participation, exercise and recreation. If your child is currently 11 years or older we'll be contacting you to see if this new study is something you and your adolescent will want to join.

When you see this logo, you'll know it's about the new study of teenagers!



We are working to share the results of our OMG Study to people all over the world. We know that others have been waiting for these results, because they believe that the curves will be helpful to the families they work with. We have written articles that we hope will be published in medical and therapy journals to share the findings widely. Eventually the goal is to make 'motor growth' curves available on the *CanChild* web page so that people can download and use them directly.

You can find the *CanChild* website at www.fhs.mcmaster.ca/canchild and if you click on "**What's New**" then "**Research in Progress**" you'll see all the research that is happening at *CanChild*. Both the Ontario Motor Growth Study (OMG Study) and the Adolescent Study of Quality of life, Mobility and Exercise (ASQME Study) are listed there. We will continue to update the website with study news and information about new publications.

AND FINALLY...HOW CAN WE THANK YOU!

How do we begin to thank **you** for contributing to this study? It must be obvious that even the best research cannot be done unless families like you give your time and energy and interest to make it possible! This partnership between *CanChild*, families of children with special needs and the children's treatment centres in Ontario is unique in the world. The work we have accomplished together, like this study and others, is making a difference around the world. We are indebted to you and your children for being part of this work, and we want to express our deep and sincere thanks for being there with us.

If you have questions about this report, or would like to know more about the OMG Study or other *CanChild* work, please contact us through the *CanChild* web page (www.fhs.mcmaster.ca/canchild), by telephone at (905) 525-9140, ext. 27850 (ask for Dr. Rosenbaum), or by e-mail at canchild@mcmaster.ca



ONTARIO MOTOR GROWTH (OMG) STUDY PROJECT REPORT

Figure 1: 'Motor growth' curves

This Figure has been removed due to copyright restrictions.

It is available at:

Prognosis for Gross Motor Function in Cerebral Palsy:

Creation of Motor Development Curves.

Peter L. Rosenbaum; Stephen D. Walter; Steven E. Hanna; et al.

JAMA. 2002;288(11):1357-1363 (doi:10.1001/jama.288.11.1357)