

# Board Update

- ▣ Recent Developments & Projects





# Children's Book Project

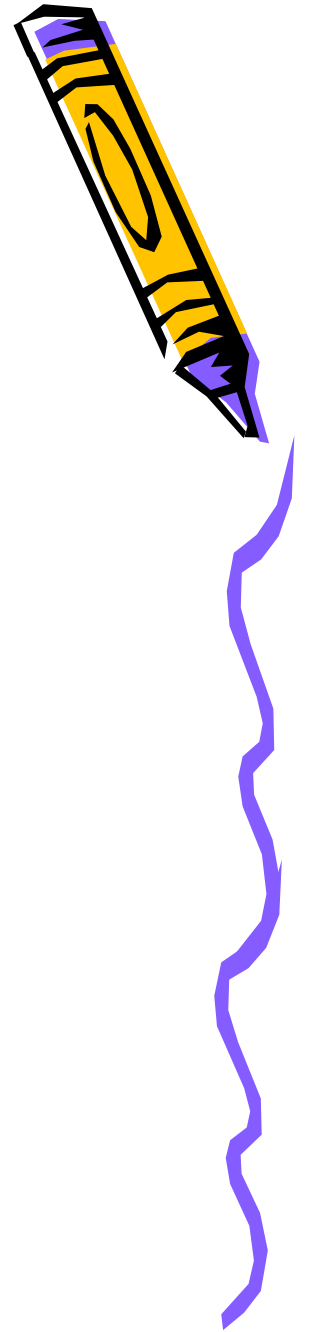
Project Coordinator: Marie Patterson

CHARGE Conference - October 2008



# Why I am me: all about CHARGE syndrome

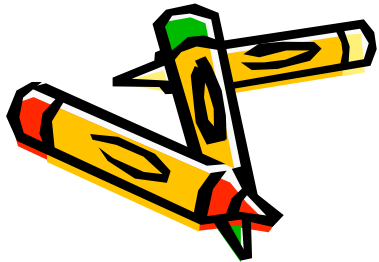
*You and I, we are the same,  
We like to laugh and play.  
Yet everyone is different,  
So I would like to say...*



*... I was born with many things That  
didn't work quite right ...*

The book uses child-friendly language so young readers can easily understand what it's like being a child with CHARGE syndrome.

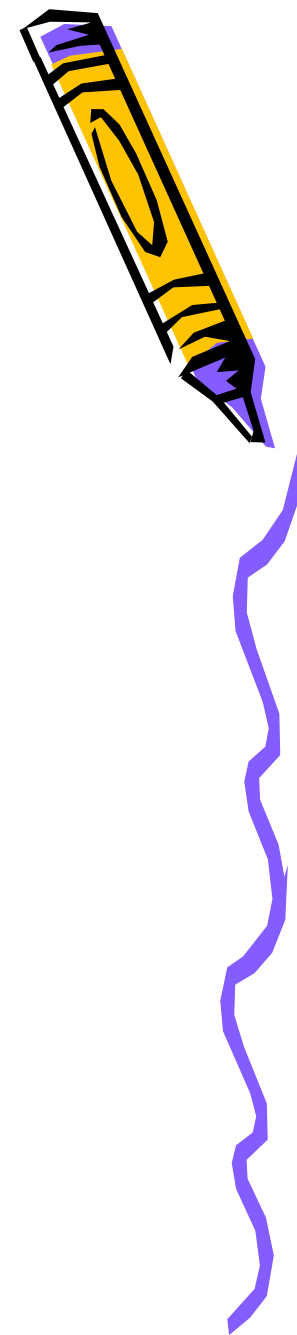
The story follows the escapades of a young boy named Sam as he makes a new friend and has fun teaching her about CHARGE.



Sam explains about the highs and lows  
of living with CHARGE syndrome:

How his coloboma affects his eyesight,  
Why he falls over easily,  
How his heart problems can slow him  
down, and  
Why he spends so much time visiting  
the doctors.

*... I may not walk the same as you,  
So I might trip and fall...*

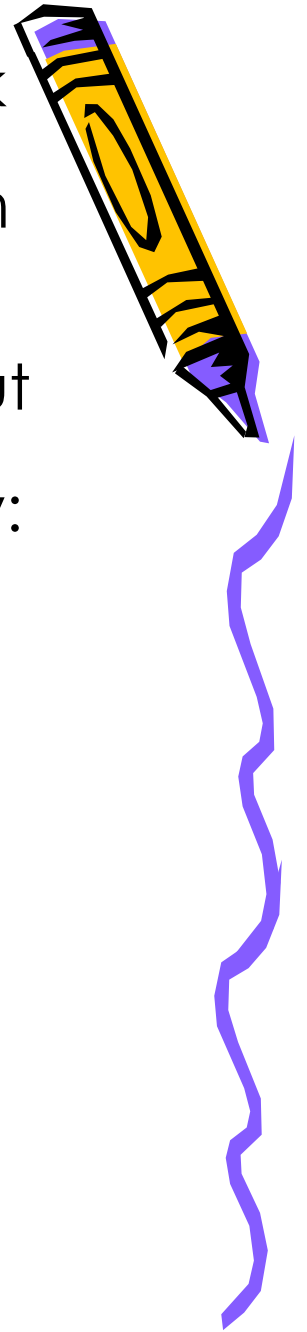


Activities are sprinkled throughout the book encouraging readers to step into CHARGE shoes and feel what CHARGE feels like from the inside.

Practical ideas appear on each page about small (and big) things we can each do to make the world a bit more CHARGE-friendly:

Slow down so I can join in,  
Look at me when you speak to me,  
Put the light source behind me if I have  
coloboma of my iris...

*I might not hear you call my name  
And so you understand:  
When you call my name again  
Please offer me your hand.*

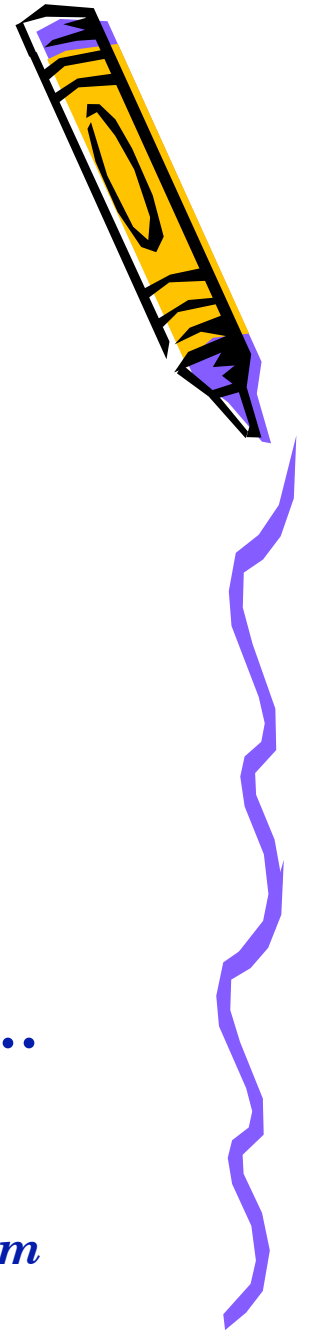
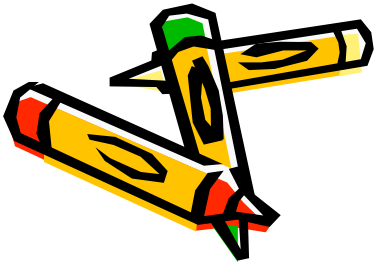


Together the children laugh and cry,  
and discover a common bond.

They trade lessons about acceptance,  
focusing on life's positives and how to  
avoid ducks and daisy bushes when  
learning to ride a bike!

*You are you and I am me  
And different we may be,  
Yet we are mates, so much the same...  
Let's race to climb that tree!*

© *Thanks to Sharon Barrey Grassick for the poem*



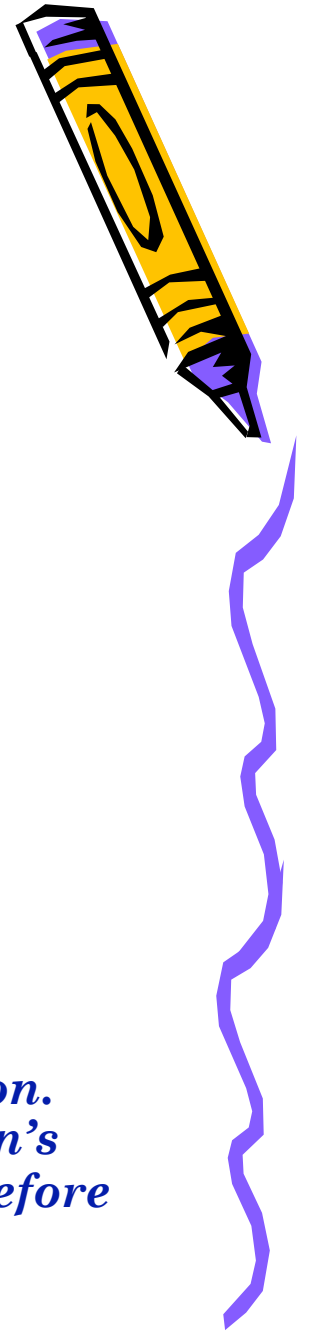
Want to read more?

This entertaining and informative book will be available early next year for distribution to schools, doctors surgeries, hospitals, libraries and any avenue that **YOU** can distribute to.

The Board will be asking you to support this venture in any way.

Pre-book your copy through the CHARGE Syndrome Association of Australasia via email or the form in your conference pack.

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Front cover  
DRAFT



# Why I am me

all about CHARGE syndrome

by Marie Patterson  
and Carry Ward

A fun-filled text bursting with facts that every child with CHARGE syndrome wishes you knew. Information that answers all your questions about CHARGE: What are the characteristic features of CHARGE syndrome? How did I get CHARGE? Will my son still have CHARGE when he's an adult? Why does my best friend spend so much time in hospital with CHARGE syndrome? Will I develop CHARGE if my brother has it? How can I help my students with CHARGE syndrome learn better? What is 'special needs'? What are grommets?

CHARGE Syndrome Association of Australasia Ltd  
[www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)

Other titles by the same publisher:

*CHARGE syndrome: Cracking the Code. A practical guide for families and professionals.*

This book is generously sponsored by:  
The Honda Foundation (Australia), Cronulla Sharks Ladies Golf Club,  
Bexley 2CH Ladies Charity Golf Club, Quota International Ingleburn  
& Club Clipsal International

ISBN # #### #### #### ##

DRAFT text  
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