

## To boldly go

'To boldly go', the theme of this year's American Academy for Cerebral Palsy and Developmental Medicine (AACPD) annual meeting, is a call to all involved with individuals with childhood-onset disabilities to drive the field forward and make a positive difference.

We are experiencing unprecedented opportunities for unique global collaborations that will enable research discoveries, attitudinal shifts, and sharing of knowledge to promote clinical excellence. The question is, can we rise to the occasion and explore new frontiers to make a difference in the field of childhood disability? The following represent personal reflections on important opportunities that can and are being realized.

### Translational Neuroscience Research Networks

There is a surge of discovery occurring in basic science at the cellular and molecular level but a schism exists between pre-clinical research and clinical application. The impact of these discoveries in the field of childhood disability could be accelerated by networks that bring together neuroscientists of varying backgrounds, including basic and clinician scientists and key stakeholders, to collaborate on setting 'cell-to-community' research goals. Two examples of such neuroscience networks are NeuroDevNet – a network of centres of excellence, focused on children with brain and neurodevelopmental disorders, and the Ontario Brain Institute Cerebral Palsy Integrated Neuroscience Discovery Network.<sup>1,2</sup> Both networks are creating mega-data related to cerebral palsy where platforms in clinical risk factors, genomics, neurodevelopment, neuroimaging, and participation are created and intersected. In addition, there are integrated, pre-clinical animal studies where the research focus is developed through a collaboration of basic and clinical scientists.

### Global Connectivity

With technological innovation, and in particular the internet, the world is indeed becoming a smaller place. We know from studies of science innovation, that bringing together the unique interactions of individuals fosters creativity. Steven Johnson in his book *Where Good Ideas Come From*, theorizes that a person with half an idea or a hunch collides with others with hunches over time, until the full 'great' idea germinates.<sup>3</sup> He argues that the internet is facilitating these 'collisions' at a faster rate. Therefore, how do we as clinicians capitalize on this 'global connectivity' to move the field of childhood disability forward? Already we see international collaborations forming that are facilitated by the ability to connect through technology. An example is the recent formation of the International Alliance of Academies of Childhood Disability (IA-

ACD) created by a virtual collaboration between the AACPD, the European Association of Childhood Disability, and the Australasian Academy of Cerebral Palsy and Developmental Medicine. This alliance aims to improve the health and well-being of children and adolescents with disabilities around the globe and is creating action plans through a virtual team spanning multiple nations.

### Harnessing Technology to Make a Difference

In addition to fostering idea sharing and communication, technology has the power to make a difference in enhancing function for individuals with disabilities, particularly through the power of inclusive universal design. Richard Ellenson, CEO of the Cerebral Palsy International Research Foundation has said: *Think of the future where an individual with gross motor functional classification level V cerebral palsy can independently drive a google car to their destination and parallel park their car upon arrival!* The world-wide-web is also allowing global access to evidence-informed care guidelines on childhood disability to drive clinical excellence and advise individuals with disabilities and their families about evidence-informed choices.<sup>4</sup>

### Wellness and Participation

We are becoming increasingly aware of the need to move away from a focus on health problems and illness to one on health and wellness for individuals with chronic disabilities. Rosenbaum and Gorter have coined what they call the six 'F' words of disability: Function, Family, Fitness, Fun, Friends, and Future.<sup>5</sup> This is powerful in its simplicity and has the potential to create attitudinal shifts in how society views disability.

Now, while all of these 'bold' ideas may generate a feeling of excitement about the future we need *action* for *impact* and I would like to suggest an additional concept: THINK GLOBAL and ACT LOCAL. This combination would allow us to think boldly but develop these thoughts into manageable, bite-size actions. So, please do *boldly go*; I look forward to sharing this journey with you!

### DARCY FEHLINGS

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