The Goal and Opportunity of Physical Therapy for Children with Down Syndrome

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The appropriate goal of physical therapy for children with Down syndrome is not to accelerate their rate of gross motor development as is commonly assumed. The goal is to minimize the development of abnormal compensatory movement patterns that children with Down syndrome are prone to develop. Early physical therapy makes a decisive difference in the long-term functional outcome of the child with Down syndrome. Beyond this goal, there is an additional opportunity that physical therapy makes available to parents. Because gross motor development is the first learning task that the child with Down syndrome encounters, it provides parents with the first opportunity to explore how their child learns. There is increasing evidence that children with Down syndrome have a unique learning style. Understanding how children with Down syndrome learn is crucial for parents who wish to facilitate the development of gross motor skills as well as facilitating success in other areas of life including language, education and the development of social skills.

The mother of an infant with Down syndrome recently asked about beginning physical therapy for her child. She began the meeting by asking: “If we start physical therapy now, what difference will it make when my child is 9 or 10 years old?” What a great question! It is exactly how she should be thinking about physical therapy, and, in fact, it is exactly how she should be thinking about all the services for her child. She has focused on the long-term functional outcome for her child. That question and that focus have guided my work for many years. This paper will answer her question. What difference, indeed, will it make years from now, when a child is an adolescent or an adult, whether or not he or she had physical therapy as a child? This article will address the goal of physical therapy for children with Down syndrome, and then looking beyond that goal, will discuss an additional opportunity that is available to parents while their child is receiving physical therapy.

THE GOAL OF PHYSICAL THERAPY

Before discussing what the goal of physical therapy for children with Down syndrome is, it is necessary first to understand what the goal is not. The goal of physical therapy is not to accelerate the rate of gross motor development. This statement is more controversial than it may initially seem to be. Many parents, many physical therapists and many insurance companies assume that the value of physical therapy can be measured by whether or not a child is achieving motor skills more quickly. Some therapeutic techniques promote themselves by saying that children who are treated with that technique develop motor skills earlier. If, however, one begins with the premise that the goal of physical therapy is to accelerate the rate of gross motor development, then one needs to answer the question posed by that mother. What difference will it make in 9 or 10 years that a child with Down syndrome walked at 21 rather than 24 months of age? How will that three-month difference affect a child’s long-term functional outcome? I do not believe that it will make any difference whatsoever, and, therefore, I do not believe that it is the appropriate goal for physical therapy for children with Down syndrome. The rate of gross motor development in children with Down syndrome is influenced by a number of factors, including:

• hypotonia
• ligamentous laxity
• decreased strength
• short arms and legs.

These factors are determined by genetics, and although some may be influenced by physical therapy, they cannot be fundamentally altered.

So then, what is the goal of physical therapy for children with Down syndrome? Children with Down syndrome attempt to compensate for their hypotonia, ligamentous laxity, decreased strength and short arms and legs by developing compensatory movement patterns, which, if allowed to persist, often develop into orthopedic and functional problems. The goal of physical therapy is to minimize the development of the compensatory movement patterns that children with Down syndrome are prone to develop.

Gait is a primary example. Ligamentous laxity, hypotonia and weakness in the legs lead to lower extremity posturing with hip abduction and external rotation, hyperextension of the knees, and pronation and eversion of the feet. (See Figure 1.) Children with Down syndrome typically learn to walk with their feet wide apart, their knees stiff, and their feet turned out. They do so because hypotonia, ligamentous laxity and weakness make their legs less stable. Locking their knees, widening their base, and rotating their feet outward are all strategies designed to increase stability. The problem is, however, that this is an inefficient gait pattern for walking. The weight is being borne on the medial (inside) borders of the feet, and the feet are designed to have the weight borne on the outside borders. If this pattern is allowed to persist, problems will develop with both the knees and the feet. Walking will become painful, and endurance will be decreased. Physical therapy should begin teaching the child with Down syndrome the proper standing posture (i.e., feet positioned under the hips and pointing straight ahead with a slight bend in the knees) when he is still very young. (See Figure 2.) With appropriate physical therapy gait problems can be minimized or avoided. (See Figure 3.)

Trunk posture is another example. Ligamentous laxity, hypotonia, and decreased strength in the trunk encourage the development of kyphosis, which is often first seen when the child is learning to sit. Children with Down syndrome typically learn to sit with a posterior pelvic tilt, trunk rounded and the head resting back on the shoulders. (See Figure 4.) They never learn to actively move their pelvis into a vertical (upright) position, and therefore, cannot

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hold their head and trunk erect over it. If this posture is allowed to persist, it will ultimately result in impaired breathing and a decreased ability to rotate the trunk. Physical therapy must teach the child the proper sitting posture by providing support at the proper level even before the child is able to sit independently. (See Figure 5.) First, the therapist provides upper trunk support, then middle trunk support, then support between the scapula and the waist, then support at the waist and finally pelvic support. The support provided at each level keeps the spine and pelvis in proper alignment until the child develops the strength to hold that segment in alignment himself. Appropriate physical therapy can minimize problems with trunk posture. (See Figure 6.)

Physical therapy services:
• should be concerned with the child’s long-term functional outcome;
• should seek to minimize the development of compensatory movement patterns;
• should be based on a thorough understanding of the compensatory movement patterns that children with Down syndrome are prone to develop;
• should be strategically designed to proactively build strength in the appropriate muscle groups so that the child with Down syndrome develops optimal movement patterns;
• should focus on gait, posture and exercise.

So the answer to that mother’s question is that physical therapy for the young child with Down syndrome will make an enormous difference not only when the child is 9 or 10 years of age, but also when he or she is an adolescent and an adult. It can and should result in adults who are healthier and more functional.
THE OPPORTUNITY OF PHYSICAL THERAPY

If physical therapy has achieved the goal of minimizing the development of abnormal movement patterns, it will have influenced the health of the child with Down syndrome throughout the course of his or her life. But there is actually an opportunity beyond the development of motor skills of which parents may wish to take advantage while their child is receiving physical therapy.

There is mounting evidence that children with Down syndrome do not learn in the same manner that typical children do. They have a different style of assimilating information, and, therefore, the usual methods of instruction are less effective. The development of gross motor skills is the first learning task that the child with Down syndrome and his parents will face together. There are many other challenges to come including language, education, and the development of social skills, but learning gross motor skills is the first developmental challenge. The opportunity is for parents to use the arena of gross motor development to begin to understand how their child learns. Knowing how to facilitate their child’s learning will be critical to their success in collaborating with their child throughout his or her lifetime.

Wishart (1991), a psychologist at the University of Edinburgh in Scotland, has done leading edge work in studying how children with Down syndrome learn. She writes:

Despite the absence of an adequate developmental database, theory and practice in this area have nonetheless continued to assume that the process of learning in children with DS is essentially a slowed-down version of normal cognitive development. An increasing number of recent studies are suggesting that this ‘slow development’ approach may be ill founded and that learning may differ significantly in structure and organization from that found in ordinary children... (p.28-29).

Infants with DS consistently showed evidence of underperforming, with avoidance routines being produced on many of the tasks presented, regardless of whether these were above or below the infant’s current developmental level. New skills, even once mastered, proved to be inadequately consolidated, often disappearing from the infant’s repertoire in subsequent months. Follow-up studies using a wider range of tasks provided additional evidence of this tendency to ‘switch out’ of cognitive tasks, with many children failing on items which should have been well within their capabilities and which had been passed in earlier sessions... (p.29).

Regardless of whether these irregular performance profiles reflect genuine developmental instability or are the result of fluctuating motivation in assessment-type situations, it remains that if test behaviour is typical of behaviour in other, everyday situations, development itself must be compromised. (p.29).

Investigation into the learning style of children with Down syndrome is in its early stages. Kumin (2001) and Oelwein (1995) also have made important contributions in this area. In her book, Classroom Language Skills for Children with Down Syndrome: A Guide for Parents and Teachers, Kumin discusses how the insights of Howard Gardner can be applied to children with Down syndrome. Gardner’s book, Frames of Mind, presents the theory of multiple intelligences, which postulates that intelligence is multi-faceted. The theory holds that besides linguistic and mathematical intelligences, there are also spatial, interpersonal and musical intelligences, to mention only a few. Kumin notes that it has been her experience that many children with Down syndrome learn well using music. She has also written about the unique learning style of children with Down syndrome, and how it pertains to learning speech and language in her book, Communication Skills in Children with Down Syndrome: A Guide for Parents and Teachers (Kumin, 1994).

Oelwein (1995) also has written about the learning style of children with Down syndrome and how it impacts education. She has highlighted the need to consciously assist children with Down syndrome with how information can be effectively filed, stored and retrieved. Her book, Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers, provides a comprehensive, step-by-step guide to teaching reading to children with Down syndrome. All of this work points to how important it is for parents to have an understanding of how their child assimilates information so that they can be successful partners in their child’s learning.

It has been my experience in 20 years of providing physical therapy to children with Down syndrome that they do indeed learn differently and that it is necessary to modify my approach if I wish to obtain the best result. I consider it an important opportunity of my work to help parents begin to understand how their child learns. The following “tips” are provided from many years of working with children with Down syndrome. They are offered to provide a starting point for both parents and therapists to begin to explore the unique learning style of the child with Down syndrome.

1. Children with Down syndrome have a decreased ability to generalize. This means that a skill learned in one setting does not necessarily transfer to another setting. For instance, a child may be quite competent climbing the stairs at home, but when confronted with stairs at the clinic, he or she may regress to a much more primitive stair-climbing strategy until he or she has relearned the skill in the new setting.

2. Children with Down syndrome need information to be delivered in small bite-sized pieces. It has been my experience that if a child appears to have plateaued, the problem is most likely to be that the next piece of information is too large and needs to be further broken down.

3. The setup is crucial and needs to be as close to perfect as possible. Children with Down syndrome need structure, consistency and a familiar environment if you hope to get their best performance. Do not try something new or challenging when the child is tired, hungry or not at his best for some reason. The quality of the work you do together is more important.
than the quantity. Minimize distractions in the environment.
4. Follow the child’s lead. The child must be motivated to perform a particular skill. Trying to impose your will on a child with Down syndrome is a losing game. I often try to model my style of interaction after the parent’s. It is familiar to the child and most likely to be successful.
5. Be attentive to how the child reacts when learning new gross motor skills. Some children are cautious, and others are risky. A cautious child prefers to stay in one position, while the risky child prefers to be in motion. For example, when learning to walk, the cautious child will want lots of support and will be upset if he or she falls. The risky child will like walking because it involves movement and will not be concerned about support or care how many times he or she falls.
6. Know when to quit. Some children will only give you two repetitions at a particular skill and then insist on moving on. Other children will gladly give you a dozen repetitions. Set up the game so that the child is successful and avoid frustration.
7. Be strategic in planning your session. Practice what the child is ready to learn. Tackle the most difficult skills first before the child becomes tired. Alternate difficult skills with easier ones to give the child time to recover his strength.
8. Be strategic in providing support. Children with Down syndrome tend to become quickly dependent on support. Provide as little support as possible while still allowing the child to succeed and remove the support as soon as possible.
9. Skills will be learned grossly at first and then refined. For instance, children will initially learn to walk with a wide base and their feet externally rotated. This is not the optimal gait pattern, but it needs to be allowed initially and then refined through the post-walking skills.
10. Do not interfere with an established skill in which the child has achieved independence. You will not be successful in introducing change and the child will only experience you as nagging. Changes will need to be made at the next level of motor development. For instance, some children, instead of learning to creep on both knees, learn to creep on one knee and one foot. Once this pattern has been established and the child is proficient in its use, you will not be successful in altering it and will succeed only in angering the child. Teach the child to use both knees in climbing up stairs rather than interfering with this established pattern.
11. Children with Down syndrome learn best through a gradual process.
   a. Introduction of the new skill is the first step. The new skill needs to be introduced slowly and carefully with the goal being simply to have the child tolerate the movement.
   b. Familiarity is the second step. In this step the child becomes accustomed to the skill and how it feels physically. This is the “I get it” phase in which the child understands the game and what is being asked of him or her.
   c. Collaboration is the third step. The child increases his collaboration and cooperation, and at the same time support is decreased.
   d. Independence is the final step where the child has mastered the skill and can perform it independently without support.

These tips are offered tentatively, knowing that they are far from definitive answers. Much more research is needed to begin truly to understand the learning style of children with Down syndrome. It is crucial, however, that parents gain skill in facilitating the learning of their child. Otherwise, as Wishart (1995) says, we “could run the risk of changing slow but willing learners into reluctant, avoidant learners.” (p. 62).

Parents who are newly assuming the responsibility of caring for a child with Down syndrome are confronted with a confusing array of treatment options and opportunities. It can be difficult to know where to focus limited time and resources. It is hoped this article will provide parents and caregivers with a starting point and a framework for making decisions about what is important. They should think about proposed therapies just like the mother described in the first paragraph, from the perspective of the child’s long-term functional outcome. Physical therapy is a crucial service, not because it will accelerate a child’s rate of development, but because it will improve a child’s long-term functional outcome by preventing the development of abnormal movement patterns that are likely to become even more serious problems in adolescence and adulthood. Secondly, because gross motor development is the first learning task a child faces, it provides parents and other caregivers with the opportunity to learn how a given child learns. The long-term functional outcome should be the guide in decisions about what to work on, and understanding of a child’s learning style should be the guide in how to work on them.

References

Book Review

Barry M. Mitnick, Ph.D.
Book Review Editor

Explaining Down Syndrome to School-Age Children


REVIEWED BY: Barry M. Mitnick, Ph.D.
University of Pittsburgh

Descriptions of the integration of children with Down syndrome into school environments often make the claim that the task of integration grows more formidable with the age of the special child. Children with Down syndrome are said to blend very well into preschool and primary classrooms, but to require aggressive social interventions in order to ensure appropriate integration by the secondary grades.

Because of the wide range of factors that affect social integration, this observation may be taken as more of a commonplace requiring careful study than an established research conclusion. It will of course be harder to integrate children with special needs into environments that have little experience with them, as was likely the case in years past. In a world in which children with Down syndrome are included with their peers from day one, the need for creating new integration will be less. Still, there can be little doubt that the complexity of environmental social effects grows with age, and that issues of how young people acquire and act upon views of their disabled (or, better, differently-abled) peers are likely to be important in building successful integrated communities.

Thus, understanding of how normal children learn about special needs peers, and how educational tools can be designed to promote such understanding, would be an important contributor to successful integration. One probably small if still important component of that overall process of social learning consists of written materials about Down syndrome. The list of publications aimed at older school-age children has been expanding (see, e.g., Bowman-Kruhm 2000; Bryan 1999; Gordon 1999; for an excellent source book on adolescents with Down syndrome, see Pueschel and Sustrova 1997).

There appears to be a market niche for such materials as school and public libraries fill out their collections with books on a variety of health and societal issues. The Franklin Watts series includes books on Alzheimer’s disease, autoimmune diseases, H.I.V., the human genome project, leukemia, Parkinson’s disease, and the focus of this review, Down syndrome. Because libraries tend to purchase multiple books from such series, ordering them off the lists, I would expect that the book on Down syndrome, offered by a major school publisher, will pop up in public and school libraries all over the country.

Contents

Although Salvatore Tocci’s Down Syndrome has several attractive features, it ultimately fails to adequately address its topic. In part, its deficits illustrate some of the key concerns in explaining Down syndrome to school-age children.

Down Syndrome takes us through a number of the standard areas that need to be covered by a review of issues in Down syndrome. After introductory chapters that provide a vignette of an unusual child with Down syndrome and a description of the manifestations of the syndrome as well as a discussion of societal roles and public sector responses, the book presents a chapter on the “causes” of Down syndrome. This is an explanation of the genetic basis for the syndrome and it is done clearly and accessibly. The book then offers a series of chapters that treat issues at different age levels. Thus the book cycles through from infancy to early school years to adolescence to adulthood. Chapters on “the family,” “the future,” and “myths and truths” fill out the book. There is also a glossary and lists of sources, further readings, and resources on Down syndrome.

The author appears to have a journalistic knowledge of Down syndrome based on a limited number of sources. The book lists only four sources, all books, that “were used for factual information and anecdotal stories about children with Down syndrome” (p. 130). Four sources were used for a book that is 144 pages in length. The publication dates of the books are 1986, 1995, 1996, and 1997 for this book with a year 2000 copyright in an area that sees new publication and new research results every year. Possibly as a result of the skimpy source list, there are glaring omissions and poor judgments about placement and content of discussions.

Down syndrome and the issues surrounding it are complex, even for those with medical or other specialties who spend a good deal of time with individuals with the syndrome. That is why the national network of clinics maintains health care guidelines (the preventive medical checklist), published in Down Syndrome Quarterly and widely re-published elsewhere. The guidelines even address some important issues that are not purely medical. This book completely ignores the checklist, which has become an essential reference representing best practices in the area. Books about Down syndrome need to be skillful in managing this complexity, without ignoring it. That applies to school-age children as well as to parents and professionals who seek to understand the condition. A book for teens that explains Down syndrome should certainly reach beyond the book list.
learn than his or her peers, inclusion can
mean placing an older child with Down
syndrome in a class of children who are
years younger. The author goes on that
“if the child becomes frustrated, learning
will not take place” and that the teacher
may “need to rely on certain strategies
to a greater extent” (p. 54).

I do not understand why a teacher’s
need to rely on “certain strategies” is at
all problematic; teachers must be
properly trained — this is not an issue,
and I do not know why it is being raised.
I read the tone of this whole section as
improperly cautionary and negative.
Yes, full, unsupported inclusion is not
likely to be the solution for all children
with Down syndrome throughout their
school careers, but I fail to see why the
benefits of making settings as
inclusionary as possible are not properly
 trumpeted here.

The author identifies five “possible
educational environments” (pp. 56-60),
from regular classrooms through various
levels of use of “additional services” and
a resource room. In my view, these do
not exhaust the possibilities and they do
not clearly present, for example, how
children may be included using a variety
of supports ranging from aides to peer
supports. To offer one example that
would not be apparent from the
presentation in this book, children with
Down syndrome can do adapted work in
a regular class, but in a way that
integrates them. Thus, the special child
can present his speech in each area of
the public speaking curriculum, just as
the other students do, only his will be
adapted, e.g., shorter and less complex.

In Tocci’s world, IEP’s are just
written and implemented (pp. 20, 54-55).
So why do peers of students with
Down syndrome see conflict between
parents and teachers and administrators
in so many settings? Why are those
meetings so long, and why do they occur
so often? In other contexts, why do
special education teachers seem to be so
frustrated so often, and so hard-
working? Tocci asserts that the child
with Down syndrome can be frustrated,
and the teacher has to use special
methods, but is the frustration coming
from a deeper source as systems fail to
provide the services they must? Can’t he
tell us about the real world and how it
works? Kids are perceptive — they can
tell the difference between mere form
and reality. The author should tell us
how and why parents often get upset at
school districts that cannot or will not
provide adequate services; at teachers
who are poorly trained or simply do not
care (and how grateful and supportive
they are when the reverse occurs); at the
cruel things that happen in schools when
some children are not recognized as
peers and allowed to participate fully
in the life of a school.

In the chapter on adolescence, Tocci
asserts in a section on personal hygiene
that “because of their dry skin, younger
children with Down syndrome may not
use soap to wash. But, during adolescence,
soap becomes a necessity.” (p.70) Not use
soap with younger children?!

The discussion of work in the
chapter on adulthood seems overly
limited and pessimistic. People with
Down syndrome hold jobs all the time,
and they do not need to be one of the
highest-functioning individuals with this
condition in order to do so. Yet the
author says “near-normal intelligence”
is necessary and goes on to a description
of sheltered workshops for the rest
(pp.87-88). This represents an older
view of what the vocational experience
of an individual with Down syndrome is
and can be.

Evidence of spotty and often
careless editing appears throughout the
book. A book that is meant as a clear
explanation should not be edited in a
way that creates questions or introduces
confusions, even little ones. For
example, a caption on page 21 under a
picture of a sign that points to a
“handicapped route” reads “Some
people with Down syndrome may not
be able to walk due to a medical problem.”
The text makes no reference to this.
What medical problem? The book
sometimes does not get names as well as
facts right. On page 128, Tocci refers to
the “American Academy of Pediatrics
Association.” On p.137, in the resources
list, Tocci makes the common mistake of
describing the National Association for Down Syndrome, a Chicago-area organization, as “a national association.”

In some places, vague language seems to be the author’s choice of how to present potentially complex subjects or fact-filled topics to younger readers. For example, in the section on questionable therapies for Down syndrome the author does not use the names most commonly applied to them, and does not mention the names of the physicians or therapists that advance them. Some, like piracetam, are just left out. I wondered if this represented a poor choice by the author, or even an editorial decision by a press worried about liability. How is anyone supposed to identify what the author is referring to? For example, if someone writes about Dr. Turkel’s vitamin regimen in another work, how will adolescent readers of this book recognize that the author has even covered it and related approaches?

I could not check all the facts in the book against the latest research, but I found myself questioning the author’s claims and/or recommendations in several places. Tocci does not use the common names for types of hearing loss or for types of disease, but does describe them. The author then says, incredibly, in regard to putting tubes in infants’ ears, “Implanting these tubes is a relatively simple procedure that can be done in a doctor’s office” (page 44). For infants with Down syndrome?! Certainly not.

Perhaps the author does not want to litter the text with medical terms, names, and other details; perhaps he thinks his largely younger readers will be put off by that. But there are ways of handling this. First, the language in the text must be absolutely correct and precise. Second, the medical terms and names can be placed in boxes, footnotes, or appendices. Vagueness by itself is never a satisfactory solution.

Some Requisites for an Adequate Introduction to Down Syndrome for School-Age Readers

The example of Tocci’s Down Syndrome does suggest some features that should be part of an adequate introduction to Down Syndrome for school-age children. If not part of available readings, they should certainly be in the relevant lesson plans as school-age children learn about their peers with special needs.

- Get the facts exactly right, and cite them. Give the readers more places to read, not only to expand the reader’s knowledge, but, especially for young people and those new to the area, to give them additional explanations of the same things. In areas that change due to new research and habilitative practices that improve treatment, note this and provide links so the readers can get to the newest stuff. No book published in 2000 or later with time-sensitive material should ignore the internet. Yes, links drop. But the major ones should be there anyway, with caveats and other ways of finding the sources (locations and phone numbers, for example). The citations should include the health care guidelines and a URL to it (the guidelines are accessible from http://www.denison.edu/dsq/) so readers can get the latest version.

- Tell it like it is, names and all: just introduce the abstruse parts in ways that can be taken in steps, e.g., in boxes. Don’t talk down to your readers (or listeners) and don’t simplify things in a patronizing way. It only generates more questions, or confused ignorance.

- Answer tough questions about things that young people observe directly. Why are the parents so upset when they talk to the special ed teachers and, especially, to the administrators? How can life in school be less than perfect for a special child? Don’t make believe systems behave the way they are supposed to. Adult systems don’t; why should those in schools and treatment systems be any different?

- If the book aims at providing a better understanding so that young people can behave more appropriately, give them explicit guidelines. What should I do if this person with Down Syndrome in my class comes over and tries to hug me? If the person has some behaviors I find annoying, how do I approach that? Should I just ignore them? How can I treat kids like these as my peers? How can I “include” them? Special education is not just a job for a special education teacher. If we value our peers with special needs as we value all others, then the job extends to us as well.

Although sections of this book are innocuous and provide adequate introductions to aspects of Down syndrome, I would never risk putting it in a school library to serve as a prime source for someone’s essay for a biology class, or in a public library to serve as a source for a parent or relative of a child with Down syndrome. Like some brands of tires, this book should be recalled by the publisher. Ultimately, a book for school-age children about Down syndrome must respect its readers as much as it says they should respect their peers with Down syndrome.

References


News from the Down Syndrome Medical Interest Group (DSMIG)

William I. Cohen, M.D. Down Syndrome Center, Children’s Hospital of Pittsburgh
Bonnie Patterson, M.D. Cincinnati Center for Developmental Disorders

Mission The Down Syndrome Medical Interest Group (DSMIG) was founded in early 1994 with the express purpose of serving as a forum for professionals addressing aspects of medical care of persons with Down syndrome. DSMIG wishes to promote the highest quality care for children and adults with DS 1) by fostering and providing professional and community education; 2) by disseminating tools for clinical care and professional support; such as the Health Guidelines for Individuals with Down Syndrome; 3) and by engaging in collaborative clinical research regarding issues related to the care of individuals with Down syndrome.

Co-Chairs

William I. Cohen, M.D. Down Syndrome Center, Children’s Hospital of Pittsburgh
Bonnie Patterson, M.D. Cincinnati Center for Developmental Disorders

W machine, I., Cohen, M.D. Down Syndrome Center, Children’s Hospital of Pittsburgh, 3705 Fifth Avenue, Pittsburgh, PA 15213. (412-692-6546; fax 412-692-5679; email: cohenb@chplink.chp.edu). 

It was a busy spring and summer for the DSMIG.

A group of members were invited to participate in the II International Conference on Chromosome 21 and Medical Research on Down Syndrome in Barcelona. This included Drs. David Patterson, Ira Lott, George Capone, Sally Shott, Bonnie Patterson and Bill Cohen. Our colleague, Dr. Augustin Seres-Santamaria, medical director of the Fundacio Catalana Sindrome de Down invited us to host DSMIG meeting immediately preceding the conference. Over 35 individuals were in attendance, and we were delighted to have an opportunity to meet with our international colleagues from Europe, Asia and South America.

Many of us participated in the National Down Syndrome Society conference in San Diego, “One Vision, One Voice.” Close to 900 individuals attended this meeting, which was designed for parents, professionals, individuals with DS and families.

Close to 60 individuals attended the DSMIG meeting on Sunday, July 8, 2001. There were two main foci: discussion of Health Care Guidelines for upcoming revision, and discussion of the other guidelines under development. Pat Winders and Alice Shea presented the overall framework for their guidelines on Gross Motor Development, as well as the specifics for children from birth to walking. Pat and Alice will be working on the other age groups, following the same overall format.

Libby Kumin presented Speech/Language guidelines in detail, soliciting revisions and editorial changes to reflect the variability of development of communication abilities of children with Down syndrome. In addition, Libby described a project to develop norms for speech/language development for children with Down syndrome. Interested individuals should contact Libby at 410-617-7623 or LBKumin@aol.com.

Copies of the Occupational Therapy guidelines, prepared by Maryanne Bruni, OTR(C), were distributed. Ms. Bruni, who was not in attendance, had prepared these previously, and they were discussed briefly.

Lastly, Bonnie Patterson distributed a draft of Behavioral Health Guidelines as prepared by her, George Capone and David Smith Ph.D. DSMIG members were asked to review them and send comments to the authors (pattb0@chncc.org).

Dawn McKenna gave a brief update on the database project of DSRF (Vancouver, BC). David Rubenson of the RAND Corporation discussed the Stanford project. Several DSMIG members, (David Patterson, Bonnie Patterson, Julie Korenberg, Ira Lott, Len Leshin, Bill Cohen) participated in a planning meeting at the end of May in Palo Alto to discuss a mechanism for integrating basic and clinical science in the area of Down syndrome studies. The planning process for that program is continuing, under the direction Dr. Bill Mobley, Chair of Neurology at Stanford University.

The afternoon session included three presentations: Peter Elliott of the Down Syndrome Research Foundation (UK) described a prospective study of antioxidants and/or folinic acid to “prevent complications of Down syndrome.” The principal investigators are xx, yy, zz, from the Institute of Child Health.

Dr. Kasuzo Iinuma (I.G. Clinic, Tokyo) presented a poster entitled “Accuracy of risk evaluation for a pregnant woman and scientific attitudes of physicians.” Dr. Iinuma’s co-investigator was K. Shimomura.

Lastly, Bill Cohen described a project in which DSMIG members and local community resources provide ‘corrective educational experiences for cognition and behavior, scheduled to take place in the fall of 2002 in Denver, CO. Watch this column for more information on the project. The next meeting of DSMIG will be held in conjunction with the NDSS/DSRF (Vancouver, BC) scientific conference on cognition and behavior, scheduled to take place in the fall of 2002 in Denver, CO. Watch this column for more information.

NDSS announces Charles J Epstein Down Syndrome Research Award. This program replaces the NDSS Science Scholar Award, and provides “seed money in grants of $5,000 to $35,000 to scientists and clinicians who seek to gain a better understanding of Down syndrome and to increase the knowledge base about this genetic condition.” For an application, contact NDSS at 1-800-221-4602.
Abstracts/References

David Smith, M.D.
Abstracts Editor

CARDIOLOGY


COMMENT: German.

COMMUNICATION

COMMENT: Review.


COMMENT: Does a statistically significant long-term effect on oral motor function translate into a clinically significant effect on speech intelligibility and communication?

DENTAL


DERMATOLOGY


EDUCATION & THERAPY

ENDOCRINOLOGY

COMMENT: A review.


COMMENT: TSH bioactivity is normal. They conclude that subclinical hypothyroidism is of thyroid (primary) origin.

EPIDEMIOLOGY


COMMENT: There has been a shift in the incidence of trisomy 21 at birth from 1/794 to 1/1606.

GASTROENTEROLOGY


COMMENT: The authors suggest testing twice for celiac disease. In their study they tested 2 years apart. Prevalence was 8% (11 individuals). I still only have one person with celiac disease and he had symptoms.


COMMENT: They had 3 cases of celiac disease out of 206 children with neurological disorders and at least one had Down syndrome. Is the increased frequency of celiac disease due to any neurologic disorder or Down syndrome?


COMMENT: A letter.

GENETICS
COMMENT: Review

COMMENT: A review.

GROWTH & DEVELOPMENT

HEMATOLOGY/ONCOLOGY

COMMENT: A letter.

COMMENT: A letter.

MISCELLANEOUS

COMMENT: A letter.

NEPHROLOGY
NEUROLOGY


COMMENT: Twenty-two individuals with varying degrees of cognitive decline were compared to 44 adults with DS who remained healthy. The duration of the longitudinal study was not evident from the abstract. They used the WISC-R to test cognitive function.


OPHTHALMOLOGY

COMMENT: Accommodation was poor, regardless of the refractive error. Glasses do not remedy the problem. Therefore near vision is consistently out of focus. Not good for reading. N=69. Age 4-85 months. Why do so many kids with DS sit so close to the TV or a book? How close is near in “near vision”? One reference mentioned using 40 cm as a test distance but also said near is an individual thing.


ORTHOPEDICS


OTOLARYNGOLOGY


**Prenatal Diagnosis**


**Comment:** A letter.


**Comment:** Review


**Comment:** A review.

**Psychiatry**


**Rheumatology**


**Comment:** A review.
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