Down Syndrome: Common Pediatric Ear, Nose and Throat Problems

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Ear, nose and throat problems are common in children with Down syndrome and these problems are closely linked to physical, emotional, and educational development. This article reviews common otolaryngologic difficulties associated with Down syndrome in children and stresses the critical need for these issues to be appropriately addressed by the child’s primary care physician and the consulting Otolaryngologist.

As the care of children with Down syndrome has become more aggressive and more pro-active, multiple ear, nose and throat problems common to children with Down syndrome have become apparent. These include an increased incidence of ear infections and hearing loss, airway problems including obstructive sleep apnea and subglottic stenosis, problems with chronic rhinorrhea and sinusitis, as well as important anesthetic considerations. These Otolaryngologic manifestations of Down syndrome need to be appropriately addressed by both the child’s primary care physician and the consulting Otolaryngologist. Whereas the relationship between hearing loss and language delay has been well documented in the past, more studies are now identifying the effects of sleep abnormalities on behavior, development and growth. Aggressive management of the otolaryngologic manifestations of Down syndrome is necessary and can be instrumental in allowing the children to achieve their full potential.

Otolologic Disease
External Ear Canal Stenosis

Stenotic ear canals can occur in up to 40% of newborns with Down syndrome (1). The very small ear canals and resultant cerumen impactions make diagnosis of any type of middle ear disease difficult. A visit to an Otolaryngologist for cleaning of the ear canals under the office microscope is frequently necessary so that appropriate examination and diagnosis can be done. An increased incidence of middle ear effusion has been associated with the stenotic ear canals. One study showed that almost 80% of patients with stenotic ear canals had middle ear effusions on exam. If there are both stenotic ear canals and chronic rhinorrhea present, a 100% incidence of middle ear effusion was reported (1). This association is most likely due to failure to visualize the tympanic membranes and the failure to appropriately diagnose and treat the presence of middle ear fluid and otitis media.

In the majority of children, the stenotic ear canals grow with age and usually by age 2 or 3 years this is no longer a deterrent to accurate examination. However, until that time, regular visits to the Otolaryngologist’s office for cleaning and evaluation of the middle ear space is necessary. Because of the growth seen in the ear canals over time, only in a small minority of patients is a reconstructive canalplasty needed to surgically enlarge the ear canals.

Chronic Ear Disease

There is an increased incidence of chronic ear disease in children with Down syndrome. There are several reasons for this. There is an increased incidence of upper respiratory tract infections, possibly due to the immaturity of the immune system. Studies have shown a reduction of both T and B lymphocyte cell function in individuals with Down syndrome (2,3). In addition, there are some structural considerations that predispose to chronic ear disease. The mid-face hypoplasia, common in children with Down syndrome, includes abnormalities in the area of the nasopharynx where there can be an abnormal insertion of the eustachian tube. In addition, the eustachian tube shape is more cylindrical and is smaller in width (4). The generalized hypotonia seen in children with Down syndrome may also cause chronic ear effusions secondary to the decreased function of the tensor veli palatini muscle of the palate. This muscle is responsible for opening and closing the eustachian tube resulting in poor eustachian tube function (1). On the histopathologic level, the decreased cartilage cell density with the eustachian tube in children with Down syndrome may contribute further to the increased incidence of eustachian tube pathology (5).

Hearing Loss

Children with Down syndrome have a 3 times higher incidence of chronic ear disease and hearing loss than other children with mental retardation (7,9). The incidence of hearing loss in children with Down syndrome has been reported to be as high as 78% (6,7,8). Multiple studies have shown a relationship between even mild hearing loss and educational, language, and emotional development (6,7,10).

Balkany et al. reported that 83% of the hearing loss seen in patients with Down syndrome was due to a ‘conductive’ or middle ear abnormality (8). Interestingly, of those with a conductive hearing loss, only 60% could be attributed to chronic ear disease such as middle ear infections or tympanic membrane perforations. This observation led them to look for other sources of the conductive hearing loss. They evaluated temporal bones and examined the middle ear ossicles at surgery. Oscillatory abnormalities were found and included congenital fixation and structural deformity of the stapes. In addition, they found erosion and/or fixation of the malleus and incus secondary to chronic inflammation. However, in 25% of the children evaluated with surgery for a conductive hearing loss, no obvious anatomic abnormalities that could explain the hearing loss was found. The reasons for this are still unclear, although Harada and Sando’s studies on temporal bone histopathology in Down syndrome postulate that remnants of mesenchyme tissue in the round window niche may contribute to this unexplained conductive hearing loss (11).

Although the majority of hearing loss is conductive in nature, between 4% and 20% of patients with Down syndrome...
may also have either a sensorineural hearing loss or a mixed hearing loss, which includes both conductive and nerve hearing loss (7,8,12).

Evaluation and treatment of hearing loss and chronic ear disease

Initial evaluation should always include a thorough exam. Otolologic and audiologic assessment are sometimes hampered by the patient’s underlying developmental delay and stenotic ear canals. This may require a visit to an Otolaryngologist for evaluation of the ears under an office microscope. Audiologic evaluations should start with a neonatal auditory brainstem response (ABR) hearing test within the first month of age. This is followed by behavioral audiologic testing every six months up to the age where the child can cooperate for an audiogram that includes pure tone testing. Initially, in young children, soundfield audiologic testing is done. This tests both ears together and does not distinguish hearing levels in the right ear from the left ear. Pure tone audiologic testing, on the other hand, provides hearing assessment and information on each ear separately. Once this is achieved, usually by age 3 or 4 years, an annual follow-up audiogram is adequate if the hearing is in the normal range. Closer observation is necessary in the presence of a hearing loss.

ABR testing evaluates the hearing via neural pathways, and can be done without the child’s cooperative participation. This type of testing can differentiate between sensorineural and moderate conductive hearing loss but can miss a mild hearing loss (13). Because of this limitation, appropriate examination and repeated testing is necessary following even a normal ABR to rule out the presence of a mild hearing loss.

Aggressive treatment of any otologic infection and/or hearing loss is advocated. In this age of managed care, referrals should not be held back if an examination is not possible because of stenotic ear canals. Both acute and chronic otitis media can contribute to both conductive and sensorineural hearing loss. Atelectasis, atrophic, and adhesive disease of the tympanic membrane as well as ossicular damage can occur if chronic middle ear effusions and infections are left untreated. The need for repeated ventilation tube or pressure equalization tube (PET) placement is common and should be expected in the majority of children with Down syndrome. Damage to the tympanic membranes is more commonly due to the chronic infections as opposed to the repeated PE tube placement.

Strome found less than 10% of the patients in his series were left with residual conductive hearing loss following treatment of the chronic otitis media. He has stressed the importance of treating patients aggressively, initially with medical treatment and then with surgical placement of ventilation tubes if middle ear fluid failed to resolve. He also noted that the treatment of the patient’s purulent rhinorhea seems to also improve the ear disease (1). Balkany et al. agreed with the need for aggressive medical and surgical management of middle ear infections. However, some limitations were identified. They found little improvement in conductive hearing loss in patients with Down syndrome who underwent reconstructive ossicular surgery for ossicular abnormalities and suggested a more conservative course such as amplification in patients who continued to have a conductive hearing loss following treatment of their chronic ear disease (8).

Amplification with hearing aids should be considered even if there is only a mild hearing loss, especially in view of the data linking mild hearing loss with delays in educational, emotional, and language development (6,7,10). Statistically significant differences in I.Q. levels were demonstrated between children with mild hearing loss due to otitis media and matched controls (6). These studies, however, were all done on otherwise normal children with hearing loss, and it should be assumed that the developmental problems associated with hearing loss may have a greater effect in children with the mental and physical handicaps associated with Down syndrome (8).

Airway Obstruction - Obstructive Sleep Apnea (OSA)

Airway obstruction is common in children with Down syndrome. Predisposing factors include mid-face and mandibular hypoplasia. The abnormally small upper airway combined with relatively large and medially positioned tonsils contribute to airway obstruction. Because of the small nasal passages and mid-face hypoplasia, nasal obstruction from secretions and nasal crusting is quite common. Adenoids tend to be relatively large in comparison to the contracted nasopharynx, which further contributes to the obstruction. Obstruction can also occur from the tongue falling back into the oropharynx during sleep. Children with Down syndrome tend to have a large tongue. This can be a true macroGLOSSIA or more commonly, a 'relative' macroGLOSSIA where the tongue appears larger than normal in the constricted oropharynx caused by the midface hypoplasia. Increased secretions, obesity, and generalized hypotonia frequently seen in Down syndrome can also contribute to oropharyngeal and hypopharyngeal collapse and obstruction during sleep.

Sleep related obstruction have been reported to occur in 50% to 100% of patients with Down syndrome (14,15,16). Marcus et al. evaluated 53 patients with Down syndrome and found that 100% had an abnormal sleep study. Obstructive sleep apnea was present in 63%, 81% had hypoventilation problems and 56% had desaturations during the studies. Age, obesity, and the presence of congenital heart disease were not predictive for the presence or absence of these sleep disturbances(14).

Obstructive sleep apnea is frequently overlooked. Studies have shown that parental observations and reports are not always a reliable way to determine if sleep disturbances are present(14,16) Many parents simply assume that their child's sleep disturbances are a normal part of the Down syndrome spectrum and are something they should just assume to be 'normal'. Marcus's studies show that in 60% of the children with abnormal sleep studies, their parents reported no sleep problems (14).

For a long time, obstructive sleep
apnea was not recognized as a potential health problem as many of the sequelae of obstructive sleep apnea disorders were conditions associated with Down syndrome, including failure to thrive, pulmonary hypertension and behavior problems. The pulmonary hypertension was primarily believed to be due to congenital heart abnormalities, present in 50% of children with Down syndrome. However, pulmonary hypertension occurs at a much higher rate than would be expected if due only to cardiac anomalies and several studies have noted an association of not only pulmonary hypertension but also heart failure with chronic upper airway obstruction (14,15,17,18).

As our understanding of sleep abnormalities in children becomes more sophisticated, the effects of sleep fragmentation and increased sleep arousals are better understood. An arousal during sleep is regarded as a protective mechanism. When one experiences an obstructive event during sleep the arousal helps to curtail the obstruction and reestablish a patent airway. Arousals occur secondarily to hypoxemia, hypercarbia and increased upper airway resistance (19). Children with Down syndrome have as much as a 3 times higher incidence of sleep arousals than the control population(16). Sleep fragmentation due to the sleep arousals has been associated with daytime sleepiness, lack of energy, and lack of initiative. Fine motor skills are also affected in adults with sleep fragmentation (20). It has been suggested that the increased arousal rate seen in children with Down syndrome may affect their daytime functioning and could exacerbate learning or behavior disorders (14).

**Obstructive Sleep Apnea – Evaluation and treatment**

Treatment of the upper airway obstruction in children with Down syndrome is dependent upon appropriate diagnosis of the source and level of the obstruction. Evaluation for airway obstruction and sleep abnormalities should include a thorough history and exam. Question the parents about their child’s sleep behaviors. Does he/she snore? Is it a mild, easy snore, or an obstructive loud snore? Does the child sleep in unusual positions – sitting up, leaning forward? Does the child seem to use a lot of effort and struggle to breathe during sleep? Are there times when the child seems to stop breathing during sleep? Does the child wake up a lot at night? In addition, is the child tired during the day? Do the poor sleeping patterns seem to effect their normal daytime activities.

Examination should include an oral and nasal exam. The amount of medial displacement of the tonsils should be noted. Observe to see if the child is a chronic mouth breather while awake. Positioning of the nasal septum and nasal obstruction from enlarged nasal turbinates should be noted. Further evaluations of the tonsils and adenoids can be done either with a lateral neck x ray or by use of a nasopharyngoscope exam. The x ray allows one to size the adenoids and their degree of obstruction in the nasopharynx and also allows visualization of the inferior extent of the tonsils. Use of the nasopharyngoscope provides similar information.

When the site of obstruction is not obvious through the usual means of oral and nasal examination as well as through the use of nasopharyngoscopy and lateral neck x-rays, sleep fluoroscopy is a useful way to demonstrate the level of the airway obstruction. Because it is a dynamic study, hypopharyngeal collapse or obstruction from the base of the tongue can be seen in this type of study.

Sleep studies or polysomnograms are used to quantitate the severity of the obstruction and help to characterize the type of obstruction. Sleep studies should be done wherever there is a question of airway obstruction that cannot be explained by obvious enlarged tonsils and adenoids. In addition, because multiple levels and locations of airway obstruction can occur in children with Down syndrome, repeat sleep studies should be done after any surgical intervention to re-evaluate for residual problems.

Sleep studies should be done overnight in a formal sleep laboratory. Nap studies and simple oxygen oximetry monitoring are not a reliable alternative. With sleep studies, obstructive hypopneas and apneas can be identified. In addition, central apnea, where the respirations are depressed centrally and not secondary to obstruction can be seen. Hypoventilation, as measured by retained end tidal PCO2 levels can be determined. In addition, sleep fragmentation with sleep arousals can be identified. Sleep studies should include the following monitors: electrocardiogram, heart rate, oxygen saturation levels by pulse oximetry, respiratory effort monitoring as measured by thoracic and abdominal Peizo crystal belts, airflow as measured by a nasal/oral thermistor, end tidal CO2 as measured by infrared absorption, pulse amplitude waves, snoring microphone, actigraph, body positioning and video monitoring, and electroencephalogram (EEG) monitoring. The EEG monitoring allowing for evaluations of sleep arousals and sleep stages.

Airway obstruction can be treated both medically and surgically. Sometimes both are needed. Use of normal saline spray can help keep the nasal passages clear improving the upper airway. This very simple therapy can lead to dramatic improvement and should not be overlooked. Medical options also include oxygen supplementation during sleep and continuous positive airway pressure (CPAP) during sleep. CPAP is the most common medical intervention used in the adult non-Down population with sleep apnea. CPAP delivers positive pressure to the airway through a tightly fitted mask worn over the nasal area during sleep. Unfortunately it is not always easily tolerated. The mask is uncomfortable to wear and the recipient must understand the need for this inconvenience. Weight reduction programs are also helpful if obesity is present.

Surgical options traditionally include removal of the tonsils and adenoids (T&A) and a procedure called an uvulopalatopharyngoplasty (UPPP). In this later procedure, in addition to removal of the tonsils and adenoids, the soft palate is trimmed, the tonsillar pillars are sutured together, and some of mucosa of the posterior pharyngeal wall is removed.

Other procedures such as mandibular advancement and tongue advancement procedures are more invasive and have not
shown consistent positive results. Tongue reduction surgery, in the presence of severe macroglottia can also be considered. Tracheotomy may be needed in severe cases of apnea and obstruction, not responsive to aggressive medical and surgical management. Other surgical options currently being investigated include the use of radiofrequency on both the base of the tongue and palate.

Unfortunately, since the obstruction can be at several different levels, traditional treatment may not be as successful as is hoped. Whereas in the non-Down syndrome population, a T&A would be expected to eliminate all of the obstructive sleep apnea, because there can be several levels of obstruction present in children with Down syndrome, the T&A may only improve the obstruction but not totally eradicate it.

Because there may still be some residual airway obstruction despite surgical intervention, it is important to obtain a postoperative sleep study to determine if further monitoring or treatment is needed. CPAP or supplemental oxygen may still be needed, although hopefully to a lesser degree.

In the case of borderline abnormal sleep studies, a repeat sleep study should be performed one year later, particularly in view of the relationship between chronic hypoxemia and chronic hypoventilation with the development of pulmonary hypertension and congestive heart failure.

**Chronic Rhinorrhea/Sinusitis**

Chronic nasal drainage or rhinorrhea is a common clinical finding in children with Down syndrome. Mid-face hypoplasia with an abnormally contracted nasopharynx results in obstruction of the nose from the adenoids. Narrowing in the area of the nose and nasal sinuses contributes to nasal obstruction, rhinorrhea and sinusitis. In addition, the immature immunologic development frequently seen in children with Down syndrome further contributes to the higher incidence of upper respiratory tract infections.

Radiologic studies have described abnormal development in the frontal, maxillary, and sphenoid sinuses including hypoplasia and total non-pneumatization of the paranasal sinuses (21). Studies have suggested that much of the rhinorrhea will improve with age, most likely due to enlargement of the anatomic abnormalities noted above with anatomic growth (1). However, with increasing emphasis on inclusion and mainstreaming, the chronic runny nose once felt to be an inevitable characteristic of Down syndrome should not be accepted. Similar chronic rhinorrhea would not be overlooked in normally developing children. Aggressive evaluation and management of the chronic rhinorrhea and sinusitis is advocated.

Assessment of chronic rhinorrhea and sinusitis includes evaluation of the upper airway to rule out nasal obstruction. Lateral neck x-rays and/or nasopharyngoscopy can be used to rule out obstruction of the posterior nasal choanae by enlarged adenoids. Evaluation of the child’s immune status can be helpful, especially in more chronic, persistent cases. This includes assessment of IgG levels, both total and subclass levels, IgA, IgM, IgE, titers to diphtheria, tetanus and pneumococcus, and possibly complement screening. Allergy testing should be considered, especially if there is a family history of environmental allergies. Risk factors such as exposure to cigarette smoke need to be identified and eliminated.

Medical management of chronic rhinorrhea and sinusitis is through the use of appropriate antibiotics and decongestants. Because of the decreased size of the nasal airway, frequent nasal crusting is common and use of normal saline spray to cleanse and moisturize the nasal passages can be extremely helpful. In children who require and respond to repeated courses of antibiotics, the short term use of a maintenance antibiotic, preferably one of limited spectrum such as Amoxicillin, should be considered. Nasal steroids are useful in controlling mild allergic-type rhinitis and its contributing effects on chronic sinusitis.

In children whose sinusitis fails to resolve with medical management, surgical intervention needs to be considered. If needed, obstruction of the nose from a deviated nasal septum or enlarged nasal turbinates should be surgically addressed. Adenoids causing blockage posterior to the nose may need excision. CT scan evaluation of the paranasal sinuses, following the use of maximum medical therapy, should be done to evaluate for chronic sinus mucosal disease and blockage of the drainage ports of the sinuses referred to as the osteomeatal complex. If these CT findings are present despite aggressive medical treatment of the sinusitis, endoscopic sinus surgery may be necessary.

**Anesthetic Considerations**

The majority of children with Down syndrome will require a surgical procedure and general anesthesia at some point in their lives. With a 50% incidence of cardiac anomalies it is quite likely that intubation of the airway will be needed. It is important that the anesthesiologist has a good understanding of the pathophysiology of children with Down syndrome. For instance, not only is there a high rate of cardiac anomalies, but the type of cardiac lesions seen in children with Down syndrome differ from the general population. Whereas 2% of all congenital heart disease is due to an atrio-ventricular septal defect, this accounts for 60% of the congenital heart anomalies in children with Down syndrome. Other medical problems that could effect the anesthetic results include pulmonary hypertension, polycythemia in the neonatal population, thyroid function abnormalities and a possible sensitivity to atropine. No differences have been noted in regards to the response of patients with Down syndrome who inhaled anesthetic agents (22).

Specific differences that may effect the outcome of a surgical procedure on a child with Down syndrome include a higher incidence of subglottic stenosis, the possibility of cervical spine abnormalities, and a potential for postoperative difficulties due to anatomic features of mid-face hypoplasia and macroglottia, predisposing the patient to upper airway obstruction in the immediate postoperative period.

**Anesthetic Considerations - Subglottic Stenosis**

An association between Down syndrome, stridor, and/or subglottic stenosis is frequently discussed in the anesthesia literature (21,22,23). It has been
common practice over the years to use a smaller endotracheal tube when intubating children with Down syndrome. A recent study confirmed that not only was the subglottic airway was smaller in children with Down syndrome but the tracheal diameter was as well (24). In order to safely intubate children with Down syndrome and not cause trauma from the endotracheal tube, a tube that is 2 sizes smaller than would be expected for the child’s age should be initially used. Sizes of endotracheal tubes are in 0.5mm increments. The appropriate size tube should be confirmed by the anesthesiologist by testing for an air leak around the inserted endotracheal tube prior to proceeding with the surgical procedure (24).

Anesthetic Considerations - Cervical Spine Abnormalities

Cervical spine abnormalities seen in Down syndrome include atlanto-axial instability (AAI), abnormal congenital fusion of the vertebral bodies, degenerative changes in the C2 – 3 and C3-4 cervical interspaces, and spinal cord compression.

Approximately 15% of patients with Down syndrome have AAI (25). Two percent will have actual subluxation and these individuals are at significant risk of spinal cord compression, especially with hyper-extension or hyper-flexion of the neck. Individuals with instability of the cervical spine are thought to be at risk for developing subluxation in the face of head and neck trauma (26,27). One of the difficulties surrounding AAI is that the majority of individuals with this type of instability are totally asymptomatic. Cervical spine films in the extension, flexion, and neutral position are currently used to document this condition. However, these films are not always reliable and the results can change from year to year (28).

It is recommended that special precautions be taken during surgery in regards to the positioning of the child with Down syndrome. Although small, there is a risk to the spinal column and because of the general anesthesia, subtle neurologic changes cannot be followed clinically. For otolaryngologic surgery, this is particularly important for T&A and major otologic surgery (29). Specifically for a T&A, hyperextension of the neck is not done in children with Down syndrome.

Despite the high incidence of PET placement, there have been no reported incidences of complications from neck positioning for short procedures such as ventilation tube placement (29).

Oral/Dental Abnormalities

A relative macroglossia is much more common than true macroglossia and is present in approximately 60% of children with Down syndrome (30). A small oral cavity, combined with decreased motor tone can exacerbate this problem. Tongue thrusting is very common and is felt to be a neurologically based behavior. With age, this improves. In addition, better tongue control and awareness of the tongue positioning improve with age. Surgical intervention is rarely necessary. Only in cases of severe obstruction from severe macroglossia should surgical reduction be considered.

Fissuring of the tongue and enlargement of the taste buds are also commonly seen in children with Down syndrome. These should be considered normal variants of the tongue architecture and no specific treatment or intervention is necessary.

Fifty percent of children with Down syndrome have missing teeth (28). Malocclusion, particularly type 3 malocclusion with mandibular protrusion and posterior cross bite occur in most children with Down syndrome. It is quite possible that upper airway obstruction and resultant dental facial changes further contribute to these dental changes.

Conclusion

Ear, nose and throat problems are common in children with Down syndrome. Parents and primary care givers need to be aware of the important role that an Otolaryngologist can play in the medical and surgical care of children with Down syndrome. Basic ear, nose, and throat problems such as ear disease and hearing loss, as well as upper airway obstruction and the potential for chronic hypoxemia are closely linked to physical, emotional, and educational development.

Fastidious diagnosis and treatment of chronic ear infections are needed to minimize the effects of chronic infections on the child’s hearing levels. The author believes that the true incidence of hearing loss in children with Down syndrome may be less than previously reported if more aggressive medical and surgical management of the chronic infections is provided to the children starting at birth. All previous studies have been retrospective in design. A prospective study is currently underway.

Further investigations into the incidence, natural history and treatment of sleep abnormalities are needed. The significance of the increased sleep arousals and sleep fragmentation seen in children with Down syndrome is still not fully understood. Treatment options for airway obstruction during sleep are unfortunately limited and need to be expanded. It is important that we aggressively address and treat these very common otolaryngologic manifestations of Down syndrome.

References


Book Review

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Images of Down Syndrome: Books for Young Children

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Not so long ago the idea that entertaining children’s literature could feature individuals with Down syndrome would have seemed like wishful thinking. A small number of books for children appeared in the 1980s, with some privately-published booklets. In the last decade, a steady stream of such books has emerged at the rate of one or two a year; four such storybooks for children appeared in 1998-99. Three additional informational books about Down syndrome for children have also been published recently, including one this year. Hence it seems like an appropriate time to take stock.

The books to be reviewed in this article are directed primarily at the early to mid primary years, and would be classified as “picturebooks,” “storybooks,” or “easy readers.” All of the books are heavily illustrated with drawings, paintings, and/or photographs, distinguishing them from the next category up, which is usually designated “juvenile fiction.” Some of the “easy readers” actually feature a more difficult level of writing and may be more suitable for more advanced readers.

There is also an intermediate class of books that are both heavily illustrated yet have stories or use language better suited for older children. A good example is Geoff Butler’s The Hangashore (1998), an unusual tale of Newfoundland with a young man with Down syndrome as a central character (see also in this group, Litchfield 1984; Thompson 1992, which does not have a central character with Down syndrome but fits in this group quite well anyway). Another group of books is designed explicitly to introduce children to Down syndrome; there are some recent publications in this area (for example, Bowman-Krumh 2000; Bryan 1999; Gordon 1999) as well as some older ones (e.g., Shalom 1984; Cairo, Cairo, and Cairo 1985). One such book, My Sister Is Special, is included in the present review because it presents itself as a story book.

The list of books reviewed below was compiled from recommendations from a local Down Syndrome Center, announcements of books or reviews that have appeared elsewhere, current books advertised or for sale at a national Down syndrome meeting, and holdings in the local county library system. As a result, some books may have been overlooked. Not all of the books may be readily available from publishers, especially the older works. I included the older works both to provide a basis for comparison and because they may still be available in the libraries of local Down syndrome groups or from public libraries. Citations and publishing information for the books are appended to this review.

Assessing the Books

In order to assess the books, their features were sorted into three main groupings: aspects of the person with Down syndrome; aspects of the setting or environment of the person with Down syndrome; and aspects of the story or presentation.

Each of the three major groupings is further subdivided. These divisions are listed in Table 1. It is not feasible to address all areas for every book, but I have tried to include most of those that prove relevant to each case.

Given their focus on books that feature individuals with Down syndrome, reviews must examine the treatment of such individuals in these works. This includes the presentation of their physical characteristics, such as their facial features, size, age, fine and gross motor abilities, athletic ability, and so on; the degree to which they display problem-solving or coping skills and specific academic skills in such areas as reading and math; and the extent of their social and life skills.

Given the importance now placed on normalization and integration, the reviews must look at how the individual’s regulatory setting is depicted, i.e., the degree of personal discretion or freedom possessed by the individual, and the inclusiveness of the individual’s settings in school, work, and social and/or home environments.

Finally, the reviews should assess the stories themselves. This includes both the content of the books and their writing and production qualities. Prominent features of the content include: the perspective (from whose point of view the story is told) and the voice (who tells the story); and the plot, which in these books tends to focus on one of three areas: adventure, search, or mystery stories; social dilemmas, relationship development, or family activities; or a new baby with Down syndrome or introduction to Down syndrome. In addition, reviews should note the emotional loading or intensity of the plot and its narrative, and the didactic content of the book in providing information about the nature or behaviors of people with Down syndrome, including the degree of central focus on Down syndrome. Aspects of the production include the nature and quality of the book’s illustrations (photographs; paintings; drawings; color or black &
Table 1

Topics for Assessing Children’s Books on Down Syndrome

Person with Down Syndrome

- Physical characteristics: e.g., facial features, size, age, fine and gross motor abilities, athletic ability, and so on.
- Ratiocination and academics:
  - Reasoning ability; problem-solving/coping abilities.
  - Academic capabilities: e.g., math, reading, other.
- Social skills/lifeskills.

Setting/Environment

- Regulatory setting; personal discretion, freedom.
- Inclusiveness of settings: school, social/home, work.

Story/Presentation

- Story content:
  - Perspective (told from whose point of view) and voice (who tells the story).
  - Plot features:
    - Adventure/search/mystery.
    - Social dilemma/relationship development/family activities focus;
      personal challenges related to goals or achievement levels.
    - New baby focus/explanation of DS, introducing people with DS and/or the impacts of DS.
    - Emotional loading/intensity.
    - Didactic content: degree of DS centrism focus (extent to which it teaches the nature or behaviors of people with Down syndrome).
- Story production:
  - Illustration: photographs; paintings; drawings; color or black & white.
  - Level of writing (e.g., appropriateness as an easy reader or picturebook).
  - Quality of writing/literary value.

white), the level of writing (e.g., appropriateness as an easy reader or picturebook), and the quality of the writing or the book’s literary value.

It is important to emphasize that the reviews are not designed to identify books that somehow score high in many of these areas; it is sufficient to find a children’s book with an engaging story, great graphics, and an accurate depiction of Down syndrome.

I will review the books grouped by plot type, because that is often the basis on which books are selected. I will begin with the adventure/search/mystery stories, because these are probably closest to traditional children’s books in theme. Then I will examine the social dilemma/relationship/family volumes. Finally, I look at those that center on new babies with Down syndrome or are clearly focused on an introduction to DS so that DS becomes the central topic of the story. Obviously, some stories overlap these areas, so that I have assigned some to a category based on my judgment of the book’s prime focus.

Stories of Adventure, Search, or Mystery

The volumes in this group typically feature a child with Down syndrome as the central character who participates in an exciting or risky series of events that take the form of an adventure, engages in a usually emotion-laden search for something, or is part of a mystery with elements that build tension that is released with the mystery’s resolution. These stories focus on the adventure, search, or mystery, rather than the fact that the protagonist has Down syndrome, although that can be a feature of the narrative.

The “Dustin” books by Alden R. Carter are among the most engaging that feature a child with Down syndrome involved in an adventure, search, or mystery. Both stories are told in the third person from the perspective of an observer or narrator via text and superb color photographs. Dustin is portrayed as a very attractive, active, social, and appealing child with Down syndrome. He is inquisitive, shows the ability to cope with problematic situations, and, in BIG School Day, displays academic abilities in class.

Dustin’s BIG School Day

In Dustin’s BIG School Day (1999), Dustin attends a regular primary school with his peers in the second grade. He is excited about an event to occur that day in school, the coming of “Dave and Skippy” to his school. In this mystery, the reader is kept in the dark about who Dave and Skippy are as Dustin rides the bus to school, attends classes, and anticipates Dave and Skippy with his friends and teachers. He finally gets to see Dave and Skippy, who turn out to be a ventriloquist and his puppet, perform for the school.

Dustin is seen in class with regular children, in a regular class with adapted materials, and in a special class with other children needing special instruction in math. He is shown interacting with regular children throughout the school day. Overall, Dustin is depicted as a delightful, enthusiastic, and competent child, well-integrated into the school.

The book does not focus at all on Down syndrome, but does show how materials may be adapted for such children and how their classes may be designed to meet their educational needs. The writing is very clear and well-suited either to be read by the child or read to the child.

Big Brother Dustin

In the earlier (1997) Big Brother Dustin, Dustin’s mother is expecting a child. Dustin is told it will be a baby girl, so presumably testing revealed the new baby’s gender. The story focuses on the search for his sister’s name. Dustin proposes several alternatives, deriving them logically from observations in his family. The book concludes with a photo album of this sister’s first few months.
As in the other volume, the clear, direct writing is suitable for reading or being read, depending on the context and reader’s level.

Again, Dustin is depicted as a capable, reasoning, and social child. He is well-integrated in his family; his grandparents are shown as obviously fond of him. The fact that Dustin has Down syndrome is incidental to the story; the book does not provide any introduction to it at all. Both of these books are good ones for new parents of a child with Down syndrome to read: They show a very attractive child who is successful both at home and at school.

**Where’s Chimpy?**

*Where’s Chimpy?* (1988) is, if nothing else, a cute book. It focuses on a beautiful little girl with Down syndrome of preschool age, Misty, who has misplaced a stuffed monkey that she needs at bedtime. The story concerns her search for the monkey. At each location she finds another lost toy until, at the end, she and her father find Chimpy. In a nice twist, she then helps her father find his misplaced glasses.

Told in the third person from the perspective of an observer, the book is illustrated with terrific color photographs. Misty appears to lead a busy life, with local friends to play with on the swings and in the sandbox, an attentive father, lots of toys that reflect an active imagination, and visits to relatives. Down syndrome is quite irrelevant to the story; there is, however, a brief introduction that describes it. This is likely to be an enjoyable book for young children to read and to listen to.

**Charlsie’s Chuckle**

In *Charlsie’s Chuckle* (1992), a seven-year-old boy with Down syndrome has an irresistible laugh that makes everyone feel better. “Bad times” have come to Charlsie’s town because the Spring rains did not fall, and the members of the Town Council have been embroiled in arguments for a month over what to do. Charlsie rides his new bicycle to the Town Hall. He overhears the council members calling one another names — pennypincher, blockhead, and so on — and creeps inside the building in order to see such remarkable-looking people. When he finds just ordinary-looking people in the meeting room, he starts laughing. That makes the Council laugh, too. Soon, they are reaching agreement on what to do for the town. The town holds a parade in Charlsie’s honor. Charlsie’s mother, who always had a sad look in her eyes, is happy.

The story is told in the third person, from the perspective of a narrator. The book is illustrated with brightly-colored photographs which follow the story, though they are not as immediately engaging as those in the Dustin books or in *Where’s Chimpy?* This is essentially an adventure, in which a boy with Down syndrome saves the town and makes his mother happy. Appended to the book is a brief description of Down syndrome.

Unfortunately, this is a well-intentioned fable that just doesn’t work. Stories like this have to be both internally plausible and appealing enough to have us suspend belief. That’s just not true here.

Charlsie takes off on his bike and rides to Town Hall. The book says his mother watches him bike away, and will not stop watching until he is home. Yet it seems strange that she does nothing when he goes downtown instead of turning around and coming back.

Things are bad in town because the Spring rains did not come. They need rain in town? The book says “The earth dried. People who had never gone hungry before had nothing to eat. And people who had always lived in nice houses had to sleep in the park” (p. 7). Because of lack of rain in one Spring?

Charlsie’s chuckle makes the Town Council laugh, and that’s enough to make them reach agreement after disagreeing for a month. Why would laughter change their minds, after a month of fighting? Good feeling does not necessarily equate with changed policies. I wonder if most young readers will understand what goes on in a Town Council and what functions government performs, at least without explanation. I don’t think I am too picky here; this is an easy reader for young children, not a fable for adults and older children.

When leaving the Council chamber, seven-year-old Charlsie says, “Excuse me, please, for interrupting your meeting” (p. 22). “Interrupting your meeting”? Would Charlsie say that?

One cannot take the conventions of a fable and graft them illogically into a story; it has to make internal sense. The photographs do not help as much as they might; they don’t take us to a fable-land, but to our neighborhood. The first photo in the book shows Charlsie getting off a school bus.

In its favor, the book shows Charlsie with normal children as friends; he does ride the bus. Like other children, he loves bikes and swings. And his chuckle makes this young boy with Down syndrome a delights to have around. Moreover, the book has a playful spirit, if an illogical one.

**Stories of Social Dilemmas and Relationships or Personal Challenges**

This group of stories focuses on problematic social relationships or on personal challenges related usually to personal goals or achievement levels. Although the personal challenges area might well represent a separate group of stories, I include them here because they often relate to the question of social integration or comparison.

**Thumbs Up, Rico!**

*Thumbs Up, Rico!* (1994) has three stories: Two are about social dilemmas; the third focuses on a personal challenge. All are told in the first person by the book’s central character, a boy with Down syndrome named Rico, and from his perspective. Rico is probably in middle school, but conceivably may be in his first year of high school; the book does not specify his age or grade level. Rico appears to attend classes in different subjects, hence the at least middle school level. He is shown to have opportunities to interact with normal children, but we are not informed about his overall level of inclusion in school. Although
extensively illustrated, this book appears to be written for upper elementary or middle school readers, i.e., the text is more like juvenile fiction. The stories are simple to understand, however, and may be appealing and generate discussion when read to elementary-age children.

In the first story, Rico befriends a normal boy who also loves to play basketball; the story traces their relationship as the initially hostile normal boy comes to know and like Rico. In the second story, Rico’s sister has to decide whether to go to a sleepover party with friends or attend an important basketball game in which Rico is playing. She has never missed any of Rico’s games. After initially telling her she must attend, Rico comes to understand that he needs to assure her that it is all right if she goes to the party. In the third story, Rico tries to draw a picture to be displayed in art class, much as those of other children in the class are displayed. After a series of failures as he tries to draw what others suggest to him, he is inspired by his dreams of basketball success to draw a picture of what he hopes to achieve in the sport. The picture receives high praise.

Rico is depicted as a verbal, social adolescent with good athletic ability. He rides a bicycle and not only plays basketball but distinguishes and performs different types of shots, understands scoring (e.g., three-point shots) and league ranking, is sensitive to different styles of play, and recognizes and is able to prompt proper techniques (e.g., bending knees for free throws). He is depicted as going to the playground by himself and giving accurate reports of his experiences.

None of this is necessarily unrealistic; there are kids like this. There are Challenger and Special Olympics leagues and teams in basketball, with children of varying abilities. Rico would certainly fall at the top end of that range. The author depicts Rico as athletically competent and perhaps unusually independent.

Rico’s first-person language is also above the level usually seen, but can be taken as reflecting his understanding more than his actual expressive language abilities. Still, the stories show Rico as reasoning, concerned over social relationships, and working hard toward reasonable goals. The stories present no direct content about Down syndrome, though there are some fairly typical incidents: Rico likes to hug; he displays perseverance in repeatedly asking his sister if she has made up her mind about attending the sleepover party.

The book is illustrated with what appear to be water-color paintings. The people in the stories are not drawn appealingly; the style has a rough edge to it. Rico’s hair is especially ragged and mop-like; it looks unkempt, though it may not be intended to look that way. Certainly, Rico need not look like the cute little Dustin of the Dustin books, but I saw no story-related reason why he should look the way he does. Indeed, although possibly unintended by the artist and author, it plays to the old stereotypical appearance of an individual with DS.

Buddy’s Shadow

Buddy of Buddy’s Shadow (1991) is a five-year-old child with Down syndrome who finds it difficult to keep up with his normal playmates in schoolyard activities. But Buddy has a secret plan to “have a best friend to run and play with.” He saves his money to buy a puppy. The puppy is named “Shadow” after his shadow frightens Buddy and his sister at night. Jamie, a normal boy who is Buddy’s neighbor and who was one of those whom Buddy could not keep up with in the schoolyard, plays with Buddy and his puppy. Buddy then does not mind that his new best friend, Shadow, runs faster than he or any of his friends.

This is a good primary-age story, though it is marred by giving Buddy some potentially inappropriate skills. Buddy is depicted as being unable to read the sign that says that new puppies cost ten dollars, yet he is shown counting his money to see if he has the necessary funds to purchase the puppy. Although not at all impossible, it seems unlikely that a child with Down syndrome who already has both addition and money recognition skills could not also read a sign with “ten dollars” on it. Moreover, such math, including money, skills typically come a bit later than early reading. Buddy’s simple expressive language, on the other hand, is quite realistic. It is clear from his playmates that Buddy is included with normal children in his school, though we do not know how integrated the classrooms are.

The book is illustrated with simple gray and red line-and-wash drawings. Although these do handle the narrative quite well, I did not find them particularly attractive or engaging. The story is told in the third person, but from Buddy’s perspective, using simple, direct language that would be easy for young children to read.

How about a Hug

How about a Hug (1988) is a perfectly delightful little book that unfortunately cannot be recommended in general, though it might be appropriate to select on occasion for young normal children. The story follows a young girl with Down syndrome (perhaps four years old?) through her day. That day includes a visit to what appears to be a therapy center in which she does PT and OT. At each event, whether meeting someone or doing a good job, she asks for or is asked for a hug.

Parents of school-age children with Down syndrome will roll their eyes at this; it sometimes requires a major and persistent behavioral intervention to assure that these kids do not hug everyone and, instead, develop appropriate means of greeting others. Hence, this book is just not at all suitable to be read to children with Down syndrome. In this day and age, perhaps sadly, it is also not appropriate to encourage hugs with each and every professional for fear that that will generalize to all adults.

Although we do not know if the child in the story also receives academic instruction, by this age children with Down syndrome should. Indeed, quite the wrong impression may be left if it seems as if such a child should only be
brought to physical and occupational therapy and hugged (loved) a lot. That’s not so bad — this is, after all, a children’s story, not a textbook — but it is also a book written deliberately about a special child. Where is the reading teacher in that too-long line of huggies?

The girl meets another special child at therapy; we do not know if she has any normal friends or just spends her time with adults and in the therapy environment. Were this not a book about a special child, that issue would not seem interesting. But given that many special children do not have frequent contact with normal peers outside of school, it becomes quite a relevant question.

The drawings, both black-and-white and color, are skillful, with photo-like realism, and depict emotions well.

**Be Good to Eddie Lee**

*Be Good to Eddie Lee* (1993) is an atmospheric slice out of a summer’s day. Set in a rural area in the South, it focuses on the relationships between three middle-school-aged children, a girl and two boys. The three are neighbors; one, Eddie Lee, has Down syndrome. Christy’s mother has told her to be good to Eddie Lee, but Christy has her doubts. Eddie Lee follows Christy and her friend JimBud into the woods, looking for frog eggs. Eddie Lee is spontaneous and enthusiastic; he goes right into the water after a salamander; he sees the beauty of the water lilies; and he finds frog eggs. Eddie Lee tells Christy not to take the eggs, out of concern for the “mama frog.”

Looking at their distorted reflections in the water, Eddie Lee says, “I like you anyway... It’s what’s here that counts,” as he puts his hand over his heart.

Obviously, the story is a tale of the growth of understanding and appreciation for differences and the things the children have in common. Eddie Lee is persistent and perceptive; he shows greater sensitivity to his environment than JimBud. We have a sense that Eddie Lee’s and Christy’s relationship will be different and more of a real friendship from now on.

There is no mention of academics other than JimBud’s telling Christy not to spell out her command to get home; Eddie can’t spell. The beautiful color illustrations are evocative of deep Summer in the South. Eddie Lee is drawn quite well as an energetic child with Down syndrome, though I suspect that some will not like the cover illustration of Eddie Lee; he appears to be saying something, but his mouth is twisted. The story is told in the third person, from Christy’s perspective. The writing reaches to be poetic in places, but may occasionally reach beyond younger readers or listeners. Although this book is classified as an easy reader, its writing slots it somewhat higher. The somewhat unusual setting, poetic language, and slice-of-a-day approach may not appeal to all young readers, especially those who want more of a story line. I personally prefer stories that better depict the competencies of people with Down syndrome; it becomes hackneyed after a while to point to their great “heart.”

Still, this is a beautifully produced volume.

**Cookie**

In *Cookie* (1999), Molly is a young child with Down syndrome who does not yet have expressive speech. In the story, Molly wants a cookie, but cannot express that wish to her parents. An early intervention teacher comes to the house for the first time, and teaches the family the signs for cookie and juice. Molly then successfully uses the signs to communicate with her parents.

This is a nice short story that makes the value of signing clear to young readers. In addition, readers or listeners will learn that a child like Molly is capable despite being unable to communicate verbally: she has preferences; she is able to push a chair so she can climb to the cookie jar.

The book is told in the third person, mostly from Molly’s perspective. The illustrations are black-and-white line drawings and simple water-colors. They do the job, though they are not particularly attractive.

There are a few issues with this book. First, no child of Molly’s age should have gone that long without early intervention. Second, Molly is shown looking at the clock and waiting after being told the visitor would come when the clock “strikes three;” surely, she can’t read time! And if she is not reading the clock, but waiting for the three chimes, how did a child who has had no intervention learn to count? Perhaps from her parents? Yet they have not worked on her communication skills.

Of course, children listening to this story won’t worry about these things; they will learn a valuable lesson about signs and how they permit communication.

**Stories that Focus on New Babies with Down syndrome or that Function as an Introduction to Down syndrome**

In this group of books, the stories focus primarily to introduce Down syndrome to the reader. A common mechanism uses the coming of a baby with DS as a way to show reactions to the baby and to suggest his or her future possibilities and relation to the family and others, as well as to explain what DS is and what its effects are. A very early (and well done) example of this genre is the privately produced book that describes the experience of the Pueschel children with their brother Chris (Pueschel, Pueschel, and Pueschel n.d.). Chris, the son of Dr. Siegfried Pueschel, passed away recently.

**We’ll Paint the Octopus Red**

In *We’ll Paint the Octopus Red* (1998), a nearly six-year-old girl gets a new baby brother with Down syndrome. Illustrated with colorful drawings, the book is told by the little girl in the first person and from her perspective. In the first part of the book, the girl speculates about things she could do with her future sibling; in the latter part of the book, after the baby is born, she asks if she will be able to do each of those things with her brother. The answer in each case is “yes,” with simple caveats like it will take a little longer or he’ll do it when he is a little older. The activities involve play or family events like going on trips. The message seems to be that the child with DS will be much like his normal sibling and be very much a loved and participating family member.
The book is sensitively and clearly written, and should be a good one for primary/elementary age children both to read and to have read to them. It has an appendix with questions and answers about Down syndrome that are exceptionally well-written for a younger audience. They include one that notes that children with DS will “learn how to read, write, do math problems, draw, play sports, and do the same things the other kids at school do. It just may take them longer to learn.”

**Veronica’s First Year**

Like *We’ll Paint the Octopus Red*, *Veronica’s First Year* (1996) describes the experience of welcoming a new baby with Down syndrome. Told from the perspective of an older brother rather than sister, the book is written in the third person. Nine-year-old Nathan anticipates the arrival of his sister, sees his father and grandmother concerned about the new child, learns Veronica has Down syndrome, visits his sister in the hospital, and learns from his father that Veronica will be older when she learns to do some things but that the family will help her to learn. Nathan helps put together a photo album of Veronica’s first year much like his own. He is especially proud of Veronica’s getting his old tricycle as a present on her first birthday. The book ends with a brief page of information about Down syndrome.

This brief book has attractive color paintings that seem to be based on photographs of real people. Although the tricycle seems gifted a bit early, this is a nice, straightforward story. The message seems to be the now-familiar one that children with Down syndrome are more similar than different from normal kids, and that they can be part of a happy family setting.

**My Sister Is Special**

Although nominally about a boy’s younger sister Rachel, who has Down syndrome, *My Sister Is Special* (1998;1984) functions essentially as an introduction to Down syndrome and an encouragement to respect people with disabilities. The book has gone through two editions, with substantial (and welcome) changes in the second edition. Because the book has had wide circulation, I will comment on both editions.

The second edition of the book is well-meaning, earnest, and warmly supportive. Although it shares some writing with the first edition, the second edition is much better edited and removes some references that seem outdated or even objectionable today. For example, in the first edition there are repeated references to “handicapped people;” the mother’s role is depicted as doing housework (with Rachel) while the father is shown explaining what Down syndrome is. And the first edition asserts that Rachel “may always have to live with Mommy and Daddy.”

As an introduction to the idea that everyone is special, the likes and dislikes of big brother Nathan (Matthew in the earlier version) and his sister Rachel are listed. The text is in the first person (Nathan’s voice) and told from Nathan’s perspective. The book declares that since all share divine creation, all are special. It is just that those with disabilities are special in different ways. This theme is repeated several times. The book exhorts people not to make fun of others and to set good examples for others. People with disabilities can do lots of things and should not have everything done for them. Rachel is “fun to play with” and Nathan “can’t imagine my family without Rachel.” Nathan learns things from her, too, because “she doesn’t care what people look like or where they live;” she’ll “be anyone’s friend — no matter what.” Rachel teaches Nathan about love and he loves his special sister. The author appended a note that has teaching suggestions; these are more useful in the later edition.

Some people may be comfortable with the sentiments in the first edition of the book and the way they are expressed. Others may bristle at the label “handicapped;” it is an expression of less-than-perfection, and hence a descriptor of lower capability and intrinsic value, despite the exhortation that such individuals should be accepted and loved. Indeed, there is a very important distinction submerged here. Activists argue that this sets up a difference between higher and lower-valued people; they are not merely different, but handicapped, even if accepted and loved in spite of themselves. Rather, we should speak of and recognize diversity and value the intrinsic strengths of the individual. People are not to be compared in capability, but accepted as unique.

The first edition was produced in the format of a “goldenbook;” the second has a softcover. The drawings in the first edition are cartoonish; the faces are virtually identical — button-nosed, wide-eyed, smiling youngsters. Rachel’s appearance does not strongly suggest Down syndrome. The second edition has more vibrant, higher contrast colors and a new illustrator. The paintings are still a little cartoon-like. Although better than the first edition, the depiction of Rachel as a child with Down syndrome is not as well done as in some of the other children’s books. The text is larger and easier for children to read. The first edition is probably too didactic to be attractive to children. The second edition reads more gracefully and more simply and is certainly better both for young children to read and to hear read. Because the book does not really have a story, I am not sure if children will want to read either edition more than once. But the second edition is a pleasant book that does offer clearly expressed, important sentiments.

Given its minimal cost (about $2), I would recommend replacing the first edition with the second where the book is already held in the collections of Down syndrome groups and centers. The book is available from Christian book store chains such as Cokesbury and Family Book Store, but can also be ordered via the usual sources. Although originating with a publisher of many books on religious topics, *My Sister Is Special* has a largely nondenominational focus; there is only one specifically Christian reference, and that occurs in the teaching notes. Thus, I view this book as suitable for use by people of many religions.
Conclusion

Children’s books featuring Down syndrome have come a long way. The fact that they exist at all seems remarkable, given the short history of emergence from the dark ages of segregation and lack of care. More often than not, these stories display an attractive child with at least some interests and/or abilities similar to those of his or her peers. Many books portray the child as able to cope and problem-solve in the regular world, though there are still unexplored opportunities to emphasize competencies as well as conformity in ordinary social settings. Indeed, he or she is frequently seen among his or her normal peers, at play and/or at school. With the exception of the last group of books, information about Down syndrome is often left either to a brief summary or is entirely absent; the stories speak for themselves. And, indeed, that may be the emerging message of children’s literature in this area: let the children, and their stories, like those of and for kids in general, speak for themselves.

References


Pueschel, Siegfried Jr., Pamela Pueschel, and Jeanette Pueschel. n.d. Our Brother. Dr. Siegfried M. Pueschel, Child Development Center, Rhode Island Hospital, 593 Eddy Street, Providence, RI 02903. Softcover. Photographs, monochrome.


Note: Some of the books are also available in hardcover library bindings and/or in "prebound" hardcover versions intended for library use; not all of these are noted above. See Books in Print.
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
Co-Chairs

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.

For further information, contact either co-chair: Bonnie Patterson at 513-559-4691 or Bill Cohen at 412-692-6546. If you are interested in being added to our mailing list, please send your name, professional title, agency, address, telephone number, fax number, and email address (if any) to William I Cohen MD, 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).

News From DSMIG

Research Conference and DSMIG Meeting in Toronto

Faithful readers of these notes are most certainly aware of the research conference to be held in Toronto, Ontario, Canada on Thursday and Friday, October 26th and 27th, 2000. New Directions in Down Syndrome Research is the second biennial scientific conference sponsored by the Down Syndrome Research Foundation and Resource Center (DSRF), Vancouver, British Columbia, Canada. The first conference was held in April, 1998 in Vancouver. This meeting is co-sponsored by the National Down Syndrome Society (NDSS) and includes such speakers as Brian Chicoine, MD, Charles Epstein, MD, Bob Haslam, MD, Julie Korenberg, MD, PhD, Digby Elliot, PhD, David Patterson, PhD, among many others. Individuals on the DSMIG mailing list have been sent a copy of the program and registration information.

DSMIG will hold its annual meeting on Wednesday, October 25, 2000, the day preceding the Scientific Conference.

If you need conference registration information, contact Jo Mills, Executive Director of the DSRF via phone 604-431-9694 or e-mail: josephin@sfu.ca

Please contact me directly at 412-692-7963 or via e-mail: cohenb@chplink.chp.edu. Please include your fax number and I will fax you a registration form for the DSMIG annual meeting.

I am pleased that our Canadian colleagues will join us for the morning; they will then meet separately in the afternoon to form a Canadian Interest Group.

The main focus of our work will be further development of guidelines specifically motor development, communication, behavior, and education. These will parallel the Health Care Guidelines that were last revised in 1999.