Finding New Friends
Facilitator's Guide

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Topic: Down Syndrome

Abstract:
Down Syndrome is the most common chromosomal abnormality of childhood, with an approximate incidence of 1/1000 live births. Primary care clinicians should be familiar with the presentation and diagnosis of Down Syndrome, and know its medical, developmental, and psychosocial manifestations. This case presents the story of an 8 year old girl with Down Syndrome who is experiencing headaches, neck pain and difficulty with peer relationships in school. Clinicians will generate a differential diagnosis for her pain and discuss management strategies.

Goal:
To provide learners with a basic understanding of Down Syndrome and management of children with mild mental retardation.

Objectives:
By the end of this session, learners will be able to:
1. List the diagnostic features of Down Syndrome and its associated complications.
2. Describe the role of the clinician in management of Down Syndrome, including: monitoring of growth/nutrition, recognition and prevention of medical complications, and participation in educational planning.
3. Describe the psychosocial stresses faced by children with Down Syndrome and their parents.

Prerequisite Case:
"When to Watch, When to Refer, When to Reassure" (Using the Denver II)

Related Cases:
"Will David Catch Up?" (Global Delay)
"The Tongue Tied Toddler" (Language Delay)
"Jesse and the School Quandary: Ready, Set, Go?" (School Readiness)

Themes:
Child Development and Behavior

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Key Words:
Down syndrome, chromosomal abnormalities, prenatal diagnosis, global delay

Bright Futures Core Concepts:
While all of the Core Concepts are included in each case, this particular case can be used to highlight communication, partnership, advocacy, and prevention/health promotion.

Materials Provided:
- Facilitator's Guide
- 3-part Case Narrative: Part I, Part II, Epilogue
- Handout #1: Girls with Down Syndrome: Physical Growth 2 to 18 Years
- Handout #2: Healthwatch for the Person with Down Syndrome
- Bibliography

Facilitator Preparation:
Facilitators should thoroughly review this guide and the other materials provided. At the end of the guide we have included a section entitled, "**Independent Learning/Prevention Exercises**," that will further stimulate group and individual education on this topic.

Suggested Format for a One Hour Session:
We anticipate that case facilitators will modify implementation of the case session to best fit their educational setting and learners. For detailed recommendations on case facilitation, please see the chapter entitled, "A Brief Guide to Facilitating Case-Discussion," found in *The Case Teaching Method; and Growth in Children and Adolescents* (book 1 of this series).

Introduction: Down Syndrome is the most common chromosomal abnormality affecting children. The syndrome involves multiple anomalies resulting from either complete or partial trisomy of chromosome 21, and is reported to have an incidence of 1/800-1/1000 live births. Prenatal diagnosis by amniocentesis is offered to all expectant women over age 35. However, the majority of children with Down Syndrome are born to women *under* age 35.

Children with Down Syndrome, and all other developmental disabilities, benefit from management by an interdisciplinary team that includes: educators, therapists (speech, occupational, physical, behavioral, etc.), parents, and a pediatric clinician. The role of the pediatric clinician is to coordinate the care, support the child and family, and to become an advocate for the child's needs.

Open the Discussion: Introduce the case title and the session goal. Explain that this will be an interactive case discussion and not a lecture. Distribute Part I of the case and ask one or more of the participants to read it aloud.

Part I

Jamie Peters is an 8-year-old girl who comes to your clinic with a complaint of headaches and neck pain. She was born at full term to a 28-year-old Gravida-2/Para-1 mother. Pregnancy was unremarkable, and birth was by normal spontaneous vaginal delivery. Apgar scores were 8 and 9. A pediatrician was called to the delivery room because

the nurses noticed that Jamie had unusual palpebral fissures, a flat occiput, and a transverse palmar crease on the left hand. Subsequent chromosomal analysis indicated that Jamie had trisomy 21 (Down Syndrome).

Her clinic record reveals that she had a small muscular ventricular septal defect that closed by the age of 18 months. She underwent surgical correction of duodenal atresia at age 3 days, and had bilateral myringotomy with insertion of drainage tubes for recurrent otitis media at age 3 years. Aside from intermittent bouts of constipation, she has been well since that time.

Developmentally, she spoke her first words at 17 months, walked at age 22 months, and completed toilet training at 4 1/2 years. She is currently in the third grade, in a mainstream classroom, and her mother reports she is able to "read at grade level." A full time teacher's aide is assigned to Jamie and one other child. Jamie also receives occupational therapy once weekly and speech therapy twice weekly. Last year, she was quite happy and well behaved in the classroom. This year, however, she has demonstrated occasional school avoidance and non-compliant behavior. She becomes somewhat oppositional when asked to transition from a favorite activity to one that is less enjoyable. For example, when recess is over she will sit on the ground and refuse to go back to class. She began to complain of headaches and neck pain three weeks ago. Her mother tells you, "*I think Jamie is complaining of these things so she won't have to go to school*."

Following this reading, ask all participants "*So what do you think about this case? What would you like to focus on during our discussion today*?" List agenda items on a blackboard or flipchart. Then use the questions below to guide the discussion. Remember that the key to successfully leading a small group is facilitation of the discussion rather than lecture. Draw as many participants as possible into the discussion. Allow silences while group members think about questions. Present material from the discussion guide only when needed to complement or redirect the group discussion.

Guiding Questions for Discussion:

What are the diagnostic features of Down Syndrome? Clinical findings associated with Down Syndrome include: atypical (often up-slanted) palpebral fissures, small nose with low nasal bridge, inner epicanthal folds, Brushfield spots (speckling on the iris), flat facial profile, brachycephaly with flat occiput, short neck, excess skin on the posterior neck, hypotonia, a tendency to keep the mouth open and the tongue protruding, small ears, hyper-flexibility of the joints, wide space between first and second toe, single palmar crease, distal position of palmar axial triradius, dysplasia of middle phalanx of the fifth finger, small stature, immature gait, reduced iliac angle, increased inter-nipple distance, diastasis recti, and others. The diagnosis is confirmed by chromosome analysis - with trisomy of all or part of chromosome 21. The most common chromosomal finding is full trisomy 21 (94%), with translocation of 21 (3.3%) and trisomy 21/normal mosaicism (2.4%) accounting for the rest. Parents of children who have a translocation should have genetic counseling and a chromosome analysis themselves.

What are the associated developmental and medical problems seen in children with Down Syndrome? Developmentally, children with Down Syndrome have global delay. The *degree* to which they are delayed, however, is quite variable. In terms of cognitive development, the majority of children will ultimately function in the mild-moderate range of mental retardation (I.Q. range of 45-65). Some will function in the borderline to low-normal range of intelligence (70-90) and relatively few are severely retarded. These children are also prone to a number of medical problems. Associated cardiac problems (40-60%) include atrial-ventricular canal defects, ventricular septal defects, atrial septal defects, Tetralogy of Fallot, and patent ductus arteriosis. Associated gastrointestinal malformations (12%) include Hirschsprung Disease,

imperforate anus, duodenal atresia, and others. During the newborn period, children with Down Syndrome are more likely to be jaundiced. Associated orthopedic problems include atlanto-axial instability (potentially life-threatening) and late hip dislocations. Ophthalmologic problems are quite common, and include refractive errors, myopia, congenital cataracts, and strabismus. Children with Down Syndrome have a relatively high incidence of recurrent otitis media, chronic sinusitis, and 70-80% may experience hearing loss. They also have significantly increased risk of primary hypothyroidism and myelodysplastic diseases (including leukemia).

What further questions would you like to ask Jamie, her parents and teachers?
Questions for Jamie: How is school going? What subjects do you like/not like? What things are hard for you? Do you have friends at school? Tell me what your teachers are like. Tell me a little more about this pain you have in your neck.
Questions for her parents: How do you think Jamie is doing in school? Does her schoolwork seem too hard for her? Does she complain (of neck pain) before going to school? Does she ever complain of neck pain after school or on weekends? Has Jamie had any falls or injuries? Does she do strenuous exercise? Does Jamie see friends outside of school? How many parties has she been invited to over the past year?
Questions for her teachers: How is Jamie doing academically? Socially? In regard to behavior? Does she need more classroom support than she is getting? Does she complain of pains or ailments while at school? What happens when she complains?

What other evaluations are indicated? Thyroid function tests can be obtained to further assess the possible causes of her constipation, although her normal linear growth is quite reassuring. To evaluate the neck pain, an examination and radiographs of the lateral cervical spine, including flexion and extension views to consider atlanto-axial instability are indicated. Jamie should have audiometry and tympanometry to exclude further hearing loss as a cause of diminished classroom function.

Distribute Part II of the case narrative and have the participants read it aloud. During the reading, distribute Handout #1: Girls with Down Syndrome: Physical Growth 2 to 18 Years, and allow a minute for participants to review it.

Part II
Jamie points to her head and over the right side of her neck when asked about the location of the pain. You ask, "*Is the pain there all the time*?"
"*No*."
"*Does the pain go anywhere else on your body? Do your legs, arms or fingertips ever feel funny or tingly*?"
"*No*."
"*What time of the day is the pain the worst*?"
"*After lunch*," she replies.
"*Is there anything that makes the pain worse*?"
"*I don't know.*"

When asked about school, she responds that she likes her teachers and the classroom activities.
"*Do you have friends in school*?"
Jamie says, "*Yes*."
"*Can you tell me the name of one of your friends*?"
She is silent.
You turn to Jamie's mother and ask, "*Does she have any play dates outside of school*?"

Mom replies, "*She occasionally invites a younger girl from the neighborhood to come and play with her. While Cindy occasionally does come over, she never invites Jamie to come to her house*."
Jamie's mother also tells you that her schoolmates have never invited Jamie to any birthday parties or out of school activities.

On physical exam, Jamie is a warm and friendly 8-year-old with the typical facial features of Down Syndrome. Her height is 126 cm. and her weight is 27 kg. Her skin is dry, and she has mild atopic dermatitis. She wears glasses and has epicanthal folds and Brushfield spots on the outer third of the iris. She has an open bite with a tongue thrust. Her tympanic membranes are dull but not injected, and the motility is mildly reduced. Her thyroid is non-palpable. Heart and lung sounds are normal. Abdominal exam reveals a midline surgical scar, and a moderate amount of palpable stool in the LLQ. Her breast and pubic hair are Tanner Stage I. You note a bilateral hallux valgus deformity. Her overall muscle tone is diminished with hyperextensibility of joints, and she has decreased truncal stability and rounding of the shoulders. There are no lateralizing neurological signs, however, and her gait is slightly immature but even. You ask her mother if Jamie has ever suddenly fallen down without apparent cause (i.e. drop attack), and she says no.

Lateral neck x-ray, including flexion and extension views, shows no evidence of occipito-atlanto or atlanto-axial instability. Her thyroid function tests are all normal. Audiometry reveals that her left ear is normal, and her right ear has mild low frequency conductive hearing loss. Her tympanogram is normal for the left, and shows negative middle ear pressure on the right.

Describe a management plan for Jamie including medical, educational, and psychological interventions and support? *Medical:* Jamie's x-rays indicate no need for restriction of most physical activity. Orthopedic surgeons, however, recommend children with Down Syndrome avoid somersaults, vigorous gymnastics, use of trampolines, and other sports that may cause neck strain or injury. Since thyroid function tests are normal, constipation can be managed with dietary interventions such as fiber, fluids, fruits and vegetables. Her middle ear effusion should be re-evaluated by a consulting otorhinolaryngologist. *Educational:* Jamie should continue receiving help from the teacher's aide within the classroom. A daily program including a high degree of structure and assistance with transitions between activities is needed. Although her parents report she is "*reading at grade level,*" the recent problems with behavior may indicate a need for an educational re-evaluation and subsequent review of her Individualized Educational Plan (IEP). Jamie may be able to *decode* words at an age appropriate level, but she is unlikely to fully *comprehend* the meaning of what she has read. *Psychological:* Jamie may benefit from a behavioral medicine consultation to assist with management of oppositional behaviors at school and at home. In addition, Jamie would benefit from social skills training, group activities outside of school (Brownies, 4-H Club, church group, etc.), and contact with another family in the area that has a child with Down Syndrome who is close to Jamie's age. The aim is to promote peer interaction in an adult-supervised setting, to foster a peer friendship, and thus enhance feelings of self-esteem.

What are the relative advantages and disadvantages of inclusion model educational programs as opposed to separate programs? Mainstream educational programs may be too difficult or too confusing for certain children with complex developmental and behavioral needs. These children may be too distracted by the large class size, and may also be quite disruptive to other children. Some teachers may be unfamiliar or uncomfortable with teaching children who have significant disabilities. However, this tends to be the exception. For the vast majority of children with developmental disabilities, mainstream education offers clear advantages and few disadvantages.

Distribute the Bibliography page and Epilogue. Ask someone to read the Epilogue aloud.

Epilogue

Following her benign medical work-up, you reassured Jamie and her mother that there was no serious medical problem underlying her neck pain. Following a consultation with a Behavioral Medicine specialist, Jamie's parents instituted a management plan that included positive reinforcement (e.g., a sticker chart with subsequent reward) for staying in school and following teacher directions. Jamie continued to complain of pain in her head and neck.

Her parents were initially reluctant to involve her in activities with other children who have developmental disabilities, as they feared that Jamie could learn additional negative behaviors. They ultimately decided to try *Special Olympics*, which has on-going activities during the entire year. Jamie found acceptance there and had a wonderful time. Her complaints of head and neck pain have progressively diminished. She is not always compliant in school and the behavioral management plan needs to be reactivated from time to time.

Refer back to group's learning agenda and summarize the key teaching points that were made. This will give the group a sense of accomplishment, and emphasize the important messages. Suggest further sources of reading or other information if there are agenda items that were not covered in the discussion.

Independent Learning/Prevention Exercises: Facilitators may wish to assign "Independent Learning/Prevention Exercises" to the group, particularly if time constraints hinder the completion of the case. The following list includes suggestions to explore the available community resources that focus on Down Syndrome, as well as other areas of pertinent interest that can be integrated during or after the session. If the exercise is done in the absence of the facilitator, learners should take notes on their experience, then discuss with a faculty member.

1. Invite the family of a child with Down Syndrome to come and speak about experiences.
2. Learn about local Special Olympics.

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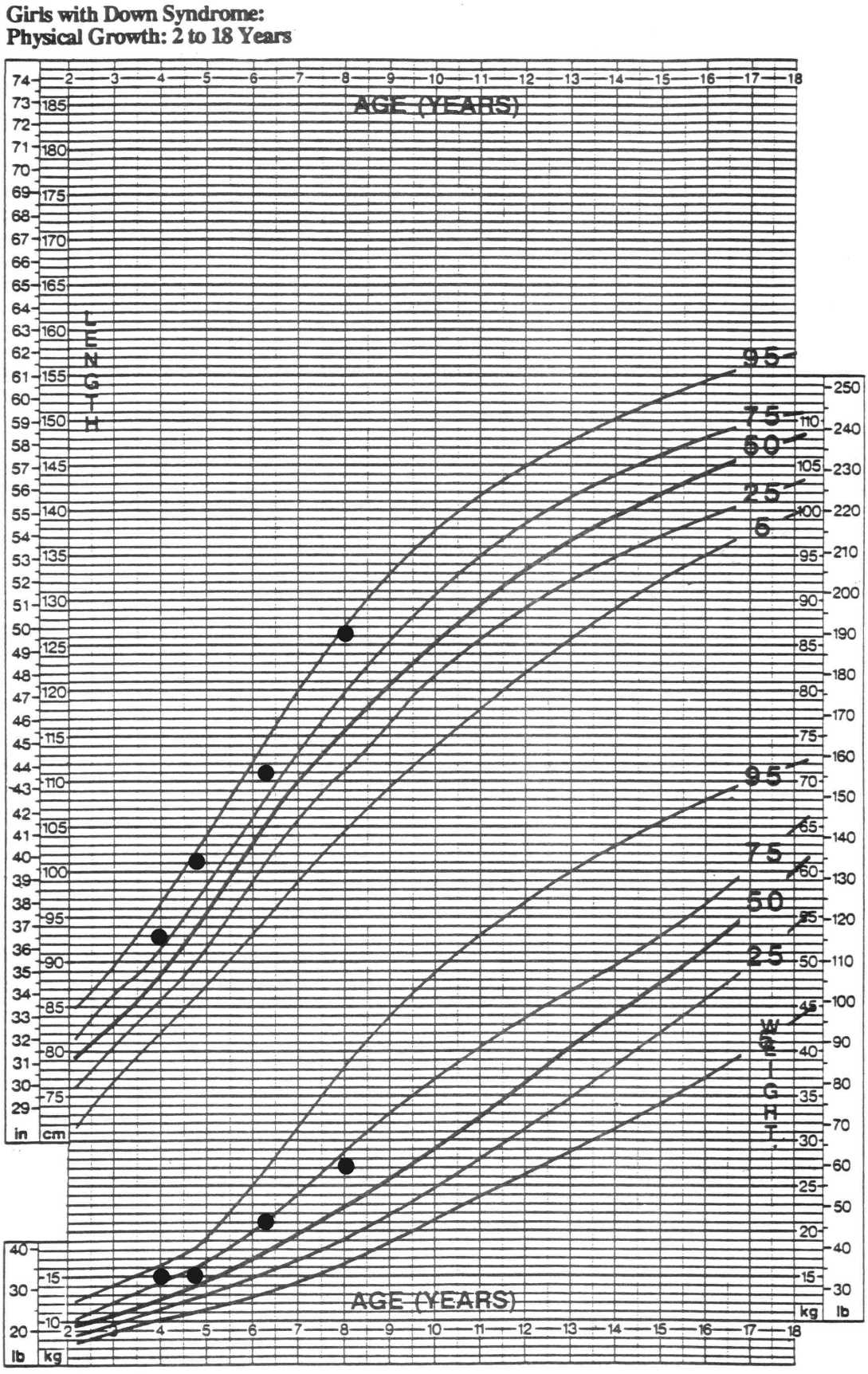
Handout #1: Girls with Down Syndrome: Physical Growth 2 to 18 Years



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Handout #2: Healthwatch for the Person with Down Syndrome

Concern	Clinical Expression	When Seen	Prevalence	Management
Congenital heart disease	AV canal defects, auricular or ventricular septal defects, Tetralogy of Fallot	Newborn or first year	40-50%	Cardiac consultation, echocardiography, surgical repair, SBE prophylaxis
Hypotonia	Reduced muscle tone, increased range of joints, motor function problems	Throughout life; improvement with maturity	All	Guidance by physical therapy; early intervention; adapted physical education
Delayed growth	Typically at or near third percentile for general population	Throughout	All	Use DS growth charts, early nutritional support; check thyroid, heart
Developmental delays	Some global delay, variable degrees; specific language problems	1st year; continues	All	Early intervention, educational planning, speech/language therapy
Hearing concerns	Serous otitis media, small ear canals, mostly conductive impairment	Check at birth or by 3 months; assess annually	Up to 50% at some times, ? 10% sensorineural	Audiology, tympanometry. ENT consultation
Ocular problems	Refractive errors Strabismus Cataracts	Eye exam at birth or by 6 months, then annual follow-ups	50% 35% 5%	Look for cataract; ophthalmologic consultation
Cervical spine abnormality	Atlantoaxial instability Potential neck of long-tract signs	X-ray at 3-5 years; repeat if symptomatic	10%± 1-2%+	Orthopedic referral; possible restriction, fusion
Thyroid disease	Hypothyroidism (rare hyper-), decreased growth and development	Some congenital; most 2nd+ decade; check at 0, 6 months, 12 months, then annually	15%	Endocrine consult, replacement therapy as needed
Overweight	Excessive weight gain	Preschool and adolescent years	Common	Lifestyle adjustment, including diet and activity
Seizure disorders	Primary generalized (also hypsarrhythmia)	Any time	5-10%	EEG, neurologic consultation
Emotional problems	Inappropriate behavior, depression, other emotional disturbances	Mid to late childhood, adult life	Common	Family guidance, aid in transitions, mental health assistance
Premature senescence	Behavioral changes, functional losses	5th, 6th decades	Unknown (increased rate)	Special support

Additional variable occurrences include congenital intestinal obstruction, Hirschsprung disease, leukemia, alopecia areata, keratoconus, hip dysplasia, diabetes mellitus, missing teeth, obstructive sleep apnea, celiac disease, and mitral valve prolapse.

Adapted from: Crocker, AC. *The Spectrum of Medical Care for Developmental Disabilities.* In: Rubin, IL, and Crocker, AC, editors. *Developmental Disabilities: Delivery of Medical Care for Children and Adults.* Philadelphia: Lea and Febinger; 1989. p.15-17, and AAP Committee on Genetics. Health supervision of children with Down Syndrome. *Pediatrics* 2001;107:442-449.

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12. Pueschel S. The Child with Down Syndrome. In Levine M, Carey W, and Crocker A, editors. *Developmental and Behavioral Pediatrics, Third edition*. Philadelphia: W.B. Saunders Co.; 1999. p. 221-228.
13. American Academy of Pediatrics Committee on Genetics. Health supervision for children with Down Syndrome. *Pediatrics* 2001;107:442-449.

Suggested Readings (Annotated):

Cooley WC, Graham JM. Down Syndrome - An update and review for the primary pediatrician. *Clinical Pediatrics* 1991; 30(4):233-253. A very practical, comprehensive, clinically-oriented guide to the background, diagnosis, and office management of Down Syndrome. Includes a helpful table on surveillance of common medical complications and growth curves for children with Down Syndrome for all genders and ages.

Pueschel S. The Child with Down Syndrome. In Levine M, Carey W, and Crocker A, editors. *Developmental and Behavioral Pediatrics, Third edition*. Philadelphia: W.B. Saunders Co.; 1999. p. 221-228. A brief overview of clinical presentation, genetics, epidemiology, developmental expectations, medical management, and counseling for parents. Written for primary care clinicians.

Roizen NJ. Down Syndrome. In: Batshaw ML, editor. *Children with Disabilities, Fourth edition.* Baltimore: Paul H. Brooks Pub. Co.; 1997. p. 361-376. This chapter includes helpful diagrams of phenotypic features, chromosomal map, and skeletal abnormalities associated with Down Syndrome. There is a table of recommendations for preventive care for both children and adolescents.

Kingsley J, Levitz M. *Count Us In: Growing Up With Down Syndrome.* New York: Harcourt Brace and Company; 1994. This book is a wonderful resource for parents and other family members who are raising children with Down Syndrome. The inspiring narrative is drawn from conversations the two authors (adults with Down Syndrome) had with family and friends, and reveals their hopes, dreams, triumphs and challenges as they grow up with a disability.

Educational Support Groups:

National Down Syndrome Congress
1800 Dempster Street
Park Ridge, IL 60068
(800) 232-NDSC

Sibling Information Network
CUAP 991 Main Street
East Hartford, CT 06108
(803) 282-7050