

KALEIDOSCOPE

The American Association for Klinefelter Syndrome Information and Support

EEOC CHALLENGES GENETIC TESTING

Feb 2001 WASHINGTON - The U. S. Equal Employment Opportunity Commission (EEOC) has filed its first court action challenging genetic testing, a Petition for a Preliminary Injunction, against Burlington Northern Santa Fe Railroad to end genetic testing of employees who have filed claims for work-related injuries based on carpal tunnel syndrome. EEOC alleges that the employees are not told of the genetic test, or asked to consent to it, and that at least one individual who has refused to provide a blood sample because he suspected it would be used for genetic testing has been threatened with imminent discharge if he fails to submit the sample.

"This is EEOC's first lawsuit challenging genetic testing. As science and technology advance, we must be vigilant and ensure that these new developments are not used in a manner that violate workers' rights," said EEOC Chairwoman Ida L. Castro. "Today, the Commission has shown that we will act quickly when confronted with such an egregious violation of the Americans with Disabilities Act as is presented here."

In its Petition, filed in U. S. District Court for the Northern District of Iowa, located in Sioux City, Iowa, the EEOC asks the Court to order the railroad to end its nationwide policy of requiring employees who have submitted claims of work-related carpal tunnel syndrome to provide blood samples which are then used for a genetic DNA test for Chromosome 17 deletion, which is claimed to predict some forms of carpal tunnel syndrome. EEOC also seeks to halt any disciplinary action or termination of the employee who has refused to submit a blood sample.

EEOC Commissioner Paul Steven Miller explained, "**The Commission takes the position that basing employment decisions on genetic testing violates the ADA.** In particular, employers may only require employees to submit to any medical examination if those examinations are job related and consistent with business necessity. Any test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee's present ability to perform his or her job." (SEE PAGE 4)

AAKSIS welcomes new board member

The Executive Director of The Genetic Alliance, Mary Davidson, LSW, has joined the AAKSIS Board. To read more about Mary, see page 3.

AAKSIS

PLANS UNDERWAY FOR 2001 AAKSIS CONFERENCE



AAKSIS will convene in Philadelphia for its second annual conference from Friday, August 3 through Sunday, August 5 at the Philadelphia Airport Marriott. To date, the list of presenters includes endocrinologists Dr. Wolfram Nolten from the University of Wisconsin Department of Endocrinology and Dr. Arturo Rolla, Harvard Medical School; Neurologist, Dr. Jay Giedd, from the National Institute of Health and leading researcher in brain studies of XXY's and variants; Psychiatrist, Dr. Jefferson Prince of Boston who will also be co-presenting with Dr. Giedd; and Mary Davidson, Executive Director of The Genetic Alliance. The agenda will also include psychological and legal professionals on topics ranging from school issues, psychological testing, and legal questions.

The popular, "Ask the Doctors Panel," will again be offered, as well as support groups for adult XXY's, parents of XXY's, and sessions for wives and significant others.

Make plans now to join us. A limited number of hotel rooms are available at a special AAKSIS rate. Further details of the conference will be available on the AAKSIS website as well on the upcoming conference brochure.

Set aside the weekend of August 3rd to explore the latest research and information, develop personal support networks, meet new friends, renew acquaintances, and enjoy the sights of Philadelphia.

In this issue

- **Introducing Mary Davidson**
- **Reader Feedback**
- **Medical Records and Your Privacy Rights**
- **Harassment Protection for Special Ed Students**
- **Understanding the thyroid gland**
- **What you need to know about hypothyroidism**
- **Depression in children and adolescents**
- **Information about bipolar disorder**
- **Medication and children**
- **The Parent Perspective**

From the
President

Dear Friends,

Almost one year has passed since AAKSIS announced its formation. Our initial hopes of reaching out to our community has become a reality as we continue to grow in membership. The challenge of trying to meet a variety of needs continually reminds me that Klinefelter Syndrome remains underdiagnosed and often misunderstood. It's hard to believe that it is already time to announce the plans for the 2001 AAKSIS National Conference. This year, the AAKSIS National Conference will take place at the Philadelphia (PA) Airport Marriott. This year's conference will bring information, support, and some surprises.

I am eagerly looking forward to renewing "in person" friendships with many of the people that I initially met via the internet, the telephone, or at previous National XXY/Klinefelter syndrome conferences. I encourage you to make the commitment to attend and to consider active involvement. We have work to do and your ideas and assistance are welcome. We can't do this alone. I am eagerly anticipating meeting many of you that I have not yet had the pleasure of meeting "in person."

Roberta

Support Groups

NEW YORK

BAYSIDE

Contact: *Grace Costa*
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STATEN ISLAND

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BOSTON AREA

NORTHEAST REGIONAL

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MIDWEST

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SOUTHEAST REGIONAL-ATLANTA AREA

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Medical consultations available as part of the AAKSIS conference

Endocrinologist, Dr. Wolfram Nolten, well respected expert on the management of Klinefelter Syndrome, will be available throughout the conference for private, individual medical consultations at no charge for attendees. The consults will be made on a first come, first serve basis.

You are cordially invited.....

Following the conclusion of the conference Penny and Mike Schwarz will host a cocktail reception for our AAKSIS community, to celebrate the engagement of Stefan Schwarz and Chris McCabe. All conference attendees are invited.

Join AAKSIS Today

Introducing Mary Davidson, newest AAKSIS Board Member

AAKSIS is proud to announce that Mary E Davidson is now a member of its Board of Directors. Mary is the Executive Director of the Alliance of Genetic Support Groups, and currently represents consumers and families on the Secretary's Advisory Committee on Genetic Testing (SACGT). Under her direction, the Genetic Alliance has grown and expanded into a strong coalition of organizations representing families, consumer advocates, health professionals, government entities and industry.

Mary is on the steering and advisory committees of many organizations, including The Genome Action Coalition (TGAC), the Coalition for Genetic Fairness, Consumer Coalition for Health Privacy, and Georgetown Law Privacy Project.

Mary has a Master's Degree in Social Work and a professional background that mixes clinical social work skills with health advocacy, community development, and organizational development. Her professional and personal experiences are broad and diverse, including community organization in the Peace Corps and several overseas work assignments in Germany, Brazil, Vietnam and Japan.

As a group, family and individual psychotherapist, Mary specialized in treating psychiatric conditions secondary to chronic health and pain problems and family issues resulting from cultural dislocation. With personal experience in genetic conditions, Mary brings both a consumer and a professional perspective to public policy and education.



KARYOTYPE

(carry-oh-type) A laptop for
word processing

READER FEEDBACK

About the Fall Issue of
KaleidoScope.....



Researchers do not truly appreciate a sentient population of study; they put our stubborn self-righteousness nature into a symptom socket instead of the self-advocacy socket. There is no way around it, if you do or you don't. All is an observed behavior worth awareness by the research community. If you put yourself out there for your fellow rat, make yourself available for and participate in the process of obtaining data, the fact that you are a self aware rat that can verbally communicate symptoms and have free thoughts of theory are invalid variables in the research process. It is in vain in getting your opinion heard and taken seriously by any professional. As sad as that is, try being examined by a new endocrinologist and having him express to your face his amazement that you have come so far in life. If he wasn't holding a particular sack of marbles at the time I might have hit him :-).

The minor reality is observed by Mr. Mulhern at the AAKSIS conference, one I have heard Dr. Nolten mutter over and over again, and one that the research community continues to battle against; --- "they have no egregious problems."

It is one of the largest Catch-22's associated with our population. The researchers battling to find significant issues and variables of a population whose major representation is walking the globe unaware of any genetic anomaly. This minor "little detail" speaks volumes for the human condition known as adaptability.

Those of us who are identified, find ourselves labeled - and thrown together into an identified pot. We know that one of our X's is inactive in any given cell (assuming all of our cells are XXY), but that doesn't rule out translocation of genes from the inactive X to the active X. Given that we don't all start out with the same genes, trying to calculate possible outcomes would seem to make the problem astronomical.

Another AAKSIS/KSA conference awareness is the observable likeness of the identified population. One might assume, given our genetic anomaly, that we would all appear similar--certainly the researchers seem to think this way! You don't need a PhD to observe that. Open your eyes and take a look.

At the next conference you might want to try an experiment of your own. Find some hotel guests, give them cameras, and have them go around and take pictures of those they suspect of being XXY. Have them fill out a simple questionnaire as to why they choose who they did and then check your data.

Perhaps we are missing the mark in all this hoopla; perhaps this is simply an endocrine issue? Perhaps that is all that it is. How we as individuals choose to adapt to our selves is our choice. Whether we choose to supply testosterone to our endocrine system or not is up to us, our self-awareness, and personal need. All the other research and speculation is as valid to us, as we, the identified population are to the researchers. It has no significant value. It is like reading the daily horoscope, some you may choose to apply, some not even close.

I realize the non-profits that are set up to assist all affected by this condition are put in an awkward situation. However, regardless of real or imagined issues, group therapy is a valued ally in any situation in life. And as these NPO's exist to assist all of us in the search for self, whether one is identified or not, taking advantage of the free resources and offering up opinions is part of the process of growth.

There is a real benefit to the group process, especially when so much ado is being projected toward a particular group. The NPO's ought to see their roles as objective educators. A group process is a tried and true method for getting to the truth of such issues, certainly for the individual. It either applies or it doesn't. If it applies to you, that doesn't mean it applies to everyone.

The fall issue of the Kaleidoscope (V1/#2) does this very well. The newsletter offers up a nice variety of information and personal opinions, as well some great resources. When it comes to an identified group such as ours, the community is what makes the group work. The individual, with his or her self-perception and a willingness to be honest and accepting within the group process, can make or break the community. So far, it appears AAKSIS is doing well to promote that idea.

What the assembled researchers dictate really needs to be taken on an individual basis. Read Christine Azzara's letter under "Parent Perspectives" in the fall issue. It speaks volumes about our nation's health care and educational systems.

A good analogy would be to treat doctor's like weather reporters--sometimes the best results are gained by using your own senses.

Sincerely,

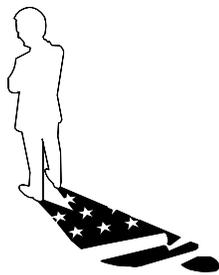
Ed Jensen

EEOC case --continued from page 1

Chester V. Bailey, Director of EEOC's Milwaukee District Office, noted that the action is based on six charges of discrimination filed with the office. Four of the charges were filed by affected individuals; two were filed by officials of the Brotherhood of Maintenance of the Way Employees on behalf of all affected union members. Bailey certified that **EEOC had determined after a preliminary investigation that "the employees would suffer irreparable injury through the invasion of their most intimate privacy rights if the practice of testing is not ended."**

EEOC is the federal agency responsible for enforcing the ADA, which prohibits discrimination against qualified individuals with disabilities, including prohibiting an employer from seeking disability related information not related to an employee's ability to perform his or her job. In addition, EEOC enforces Title VII of the Civil Rights Act of 1964, which prohibits discrimination on the bases of race, color, religion, sex or national origin; the Age Discrimination in Employment Act, which protects workers age 40 and older; and the Equal Pay Act which prohibits sex-based differences in compensation. Further information about EEOC is available on the agency's Web site at www.eeoc.gov.

Federal Equal Employment Opportunity (EEOC)



What are the federal laws prohibiting job discrimination?

- **Title VII of the Civil Rights Act of 1964 (Title VII)**, which prohibits employment discrimination based on race, color, religion, sex, or national origin;
- **The Equal Pay Act of 1963 (EPA)**, which protects men and women who perform substantially equal work in the same establishment from sex-based wage discrimination;
- **The Age Discrimination in Employment Act of 1967 (ADEA)**, which protects individuals who are 40 years of age or older;
- **Title I of the Americans with Disabilities Act of 1990 (ADA)**, which prohibits employment discrimination against qualified individuals with disabilities in the private sector, and in state and local governments;
- **Section 501 of the Rehabilitation Act of 1973**, which prohibits discrimination against qualified individuals with disabilities who work in the federal government; and
- **The Civil Rights Act of 1991**, which provides monetary damages in cases of intentional employment discrimination.

The Equal Employment Opportunity Commission (EEOC) enforces all of these laws. EEOC also provides oversight and coordination of all federal equal employment opportunity regulations, practices, and policies.

HHS establishes national standards to protect patients' personal medical records



Former HHS Secretary Donna E. Shalala released the nation's first-ever standards for protecting the privacy of Americans' personal health records in December 2000. This new regulation will protect medical records and other personal health information maintained by health care providers, hospitals, health plans and health insurers, and health care clearinghouses.

"For the first time, all Americans -- no matter where they live, no matter where they get their health care -- will have protections for their most private personal information, their health records," Secretary Shalala said. "Gone are the days when our family doctor kept our records sealed away in an office file cabinet. Patient information is now accessed and exchanged quickly. With these standards, all Americans will be able to have confidence that their personal health information will be protected."

The regulation was mandated by Congress when it failed to pass comprehensive privacy legislation. The new standards: limit

the non-consensual use and release of private health information; give patients new rights to access their medical records and to know who else has accessed them; restrict most disclosure of health information to the minimum needed for the intended purpose; establish new criminal and civil sanctions for improper use or disclosure; and establish new requirements for access to records by researchers and others.

HHS received more than 52,000 comments on its proposed privacy rule published last year. The standards announced today further strengthen patients' protection and control over their health information by extending coverage to personal medical records in all forms -- including paper records and oral communications. The earlier proposal had applied to electronic records and to any paper records that had at some point existed in electronic form. The final regulation provides protection for paper, oral and electronic information, creating a privacy system that covers all personal health information created or held by covered entities.

"Comprehensive protection of personal medical records is what Congress called for in the law, and it's what American patients and their providers want and need," Shalala said. "Protection for all records is the most logical, workable and understandable approach for patients and providers alike."

The final rule also requires that most providers get their patients' consent for routine use and disclosure of health records, in addition to requiring their authorization for non-routine disclosures. The earlier version had proposed allowing routine disclosures without advance consent -- disclosures for purposes of treatment, payment and health care operations (such as internal data gathering by a provider or health care plan). But most of those commenting on this provision, including many physicians, believed consent even for these routine purposes should be obtained in advance. Advance written consent for routine purposes will be similar to the practice most patients are accustomed to when they visit a doctor or hospital today. However, the regulation will provide additional protection by requiring that patients must also be given detailed written information on their privacy rights and how their information will be used.

Other changes from the proposed rule include--

- Allowing disclosure of the full medical record to providers for purposes of treatment: For most disclosures, such as health information submitted with bills, providers may send only the minimum information needed for the purpose of the disclosure. However, for purposes of treatment, health care providers need to be able to transmit fuller information to other providers. The final rule gives providers full discretion in determining what personal health information to include when sending patients' medical records to other providers for treatment purposes.

- Protecting against unauthorized use of medical records for employment purposes: Companies that sponsor health plans will not be able to access personal health information from the sponsored plan for employment-related purposes, without authorization from the patient.

The bipartisan Health Insurance Portability and Accountability Act of 1996 (HIPAA) called on Congress to enact comprehensive national medical record privacy standards by Aug. 21, 1999. When

Congress was unable to enact standards by this deadline, HIPAA required that HHS issue regulations. Proposed regulations were published Nov. 3, 1999. Today's issuance of final regulations completes HHS' regulatory process on health information privacy under the HIPAA provision. The regulation will be enforced by the HHS Office for Civil Rights.

The final regulation retains the approach originally outlined by Secretary Shalala in September 1997 in her "Recommendations for Protecting the Confidentiality of Individually Identifiable Health Information." The new regulation reflects the five basic principles outlined at that time.

a. Consumer Control:

The regulation provides consumers with critical new rights to control the release of their medical information, including: advance consent for most disclosures of health information; the right to see a copy of their health records; the right to request a correction to their health records; the right to obtain documentation of disclosures of their health information; and the right to an explanation of their privacy rights and how their information may be used or disclosed.

b. Boundaries:

With few exceptions, an individual's health care information should be used for health purposes only, including treatment and payment. For example, a hospital may use personal health information to provide care, teach, train, conduct research and ensure quality. However, employers who also sponsor health plans may not obtain information for non-health purposes like hiring, firing or determining promotions, without permission from the individual. Similarly, insurers may not use such information to underwrite other products, such as life insurance. Disclosure is to be kept to the minimum information needed for the purpose of the disclosure.

c. Accountability:

Under HIPAA, for the first time, there will be specific federal penalties if a patient's right to privacy is violated. For non-criminal violations of the privacy standards by the persons subject to the standards, including disclosures made in error, there are civil monetary penalties of \$100 per violation up to \$25,000 per year, per standard. In addition, criminal penalties are provided in HIPAA for certain types of violations of the statute that are done knowingly: up to \$50,000 and one year in prison for obtaining or disclosing protected health information; up to \$100,000 and up to five years in prison for obtaining or disclosing protected health information under "false pretenses;" and up to \$250,000 and up to 10 years in prison for obtaining protected health information with the internet to sell, transfer or use it for commercial advantage, personal gain or malicious harm.

d. Public Responsibility:

The new standards reflect the need to balance privacy protections with the public responsibility to support such national priorities as protecting public health, conducting medical research, improving the quality of care, and fighting health care fraud and abuse. For example, when there is an infectious disease outbreak, public health agencies need to obtain important information to better protect the public. The new regulation provides standards for how such information should be released to balance privacy and public health needs.

e. Security:

It is the responsibility of organizations that are entrusted with health information to protect it against deliberate or inadvertent misuse or disclosure. The final regulation requires covered organizations to establish clear procedures to protect patients' privacy, including designating an official to establish and monitor the entity's privacy practices and training.

The new regulation is designed to enhance the protections afforded by many existing state laws. In circumstances where the federal rules and state laws are in conflict, the stronger privacy protection would prevail. The standards apply to all consumers whether they are privately insured, uninsured or participants in public programs such as Medicare or Medicaid. Most covered entities will have two years to come into compliance.

Recognizing the savings and cost potential of standardizing electronic claims processing and protecting privacy and security, the Congress provided in HIPAA 1996 that the overall financial impact of the HIPAA regulations reduce costs. As such, the financial assessment of the privacy regulation includes the 10-year \$29.9 billion savings HHS projects for the recently released electronic claims regulation and the projected \$17.6 billion in costs projected for the privacy regulation. This produces a net savings of approximately \$12.3 billion for the health care delivery system.

While the regulation announced recently, significantly strengthens protections for patients' confidentiality, Secretary Shalala said Congress still needs to act in areas not covered by existing federal law. Under current law, the final regulation does not directly regulate many entities, including life insurers and worker's compensation programs - thus allowing unlimited use and reuse of information by such entities. Federal legislation is also needed to fortify the penalties and to create a private right of action so that citizens can hold health plans and providers directly accountable for inappropriate and harmful disclosures of information.

For updates on this regulation, see www.eeoc.gov.

US Dept. Of Education speaks out on special ed harassment

School issues of bullying and violence continue to grab headlines. Students with disabilities face challenges not only in academics, but also as targets for insensitive remarks that criticize, humiliate, and intimidate.



The following article is a communique from the US Department of Education sent to the nation's school principals, superintendents, college and university presidents. The message addresses disability harassment and apprises these leaders of their responsibilities to students with disabilities. *KaleidoScope* hopes this information will provide you with the facts regarding a school's obligation to ensure education in a safe atmosphere.

**UNITED STATES DEPARTMENT OF EDUCATION
WASHINGTON, D.C. 20202 July 25, 2000**

Dear Colleague:

On behalf of the Office for Civil Rights (OCR) and the Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education, we are writing to you about a vital issue that affects students in school-harassment based on disability. Our purpose in writing is to develop greater awareness of this issue, to remind interested persons of the legal and educational responsibilities that institutions have to prevent and appropriately respond to disability harassment, and to suggest measures that school officials should take to address this very serious problem. This letter is not an exhaustive legal analysis. Rather, it is intended to provide a useful overview of the existing legal and educational principles related to this important issue.

Why disability harassment is such an important issue

Through a variety of sources, both OCR and OSERS have become aware of concerns about disability harassment in elementary and secondary schools and colleges and universities. In a series of conference calls with OSERS staff, for example, parents, disabled persons, and advocates for students with disabilities raised disability harassment as an issue that was very important to them. OCR's complaint workload has reflected a steady pace of allegations regarding this issue, while the number of court cases involving allegations of disability harassment has risen. OCR and OSERS recently conducted a joint focus group where we heard about the often devastating effects on students of disability harassment that ranged from abusive jokes, crude name-calling, threats, and bullying, to sexual and physical assault by teachers and other students.

We take these concerns very seriously. Disability harassment can have a profound impact on students, raise safety concerns, and erode efforts to ensure that students with disabilities have equal access to the myriad benefits that an education offers. Indeed, harassment can seriously interfere with the ability of students with disabilities to receive the education critical to their advancement. We are committed to doing all that we can to help prevent and respond to disability harassment and lessen the harm of any harassing conduct that has occurred. We seek your support in a joint effort to address this critical issue and to promote such efforts among educators who deal with students daily.

What laws apply to disability harassment

Schools, colleges, universities, and other educational institutions have a responsibility to ensure equal educational opportunities for all students, including students with disabilities. This responsibility is based on Section 504 of the Rehabilitation Act of 1973 (Section 504) and Title II of the Americans with Disabilities Act of 1990 (Title II), which are enforced by OCR. Section 504 covers all schools, school districts, and colleges and universities receiving federal funds. Title II covers all state and local entities, including school districts and public institutions of higher education, whether or not they receive federal funds. Disability harassment is a form of discrimination prohibited by Section 504 and Title II. Both Section 504 and Title II provide

parents and students with grievance procedures and due process remedies at the local level. Individuals and organizations also may file complaints with OCR.

States and school districts also have a responsibility under Section 504, Title II, and the Individuals with Disabilities Education Act (IDEA), which is enforced by OSERS, to ensure that a free appropriate public education (FAPE) is made available to eligible students with disabilities. Disability harassment may result in a denial of FAPE under these statutes. Parents may initiate administrative due process procedures under IDEA, Section 504, or Title II to address a denial of FAPE, including a denial that results from disability harassment. Individuals and organizations also may file complaints with OCR, alleging a denial of FAPE that results from disability harassment. In addition, an individual or organization may file a complaint alleging a violation of IDEA under separate procedures with the state educational agency. State compliance with IDEA, including compliance with FAPE requirements, is monitored by OSERS Office of Special Education Programs (OSEP).

Harassing conduct also may violate state and local civil rights, child abuse, and criminal laws. Some of these laws may impose obligations on educational institutions to contact or coordinate with state or local agencies or police with respect to disability harassment in some cases; failure to follow appropriate procedures under these laws could result in action against an educational institution. Many states and educational institutions also have addressed disability harassment in their general anti-harassment policies.

Disability harassment may deny a student an equal opportunity to education under section 504 or Title II

Disability harassment under Section 504 and Title II is intimidation or abusive behavior toward a student based on disability that creates a hostile environment by interfering with or denying a student's participation in or receipt of benefits, services, or opportunities in the institution's program. Harassing conduct may take many forms, including verbal acts and name-calling, as well as nonverbal behavior, such as graphic and written statements, or conduct that is physically threatening, harmful, or humiliating.

When harassing conduct is sufficiently severe, persistent, or pervasive that it creates a hostile environment, it can violate a student's rights under the Section 504 and Title II regulations. A hostile environment may exist even if there are no tangible effects on the student where the harassment is serious enough to adversely affect the student's ability to participate in or benefit from the educational program. Examples of harassment that could create a hostile environment follow from school for required services related to the student's disability.

- Several students continually remark out loud to other students during class that a student with dyslexia is "retarded" or "deaf and dumb" and does not belong in the class; as a result, the harassed student has difficulty doing work in class and his grades decline.

- A student repeatedly places classroom furniture or other objects in the path of classmates who use wheelchairs, impeding the classmates' ability to enter the classroom.

- A teacher subjects a student to inappropriate physical restraint because of conduct related to his disability, with the result that the student tries to avoid school through increased absences.

- A school administrator repeatedly denies a student with a disability access to lunch, field trips, assemblies, and extracurricular activities as punishment for taking time off from school for required services related to the student's disability.

- A professor repeatedly belittles and criticizes a student with a disability for using accommodations in class, with the result that the student is so discouraged that she has great difficulty performing in class and learning.

- Students continually taunt or belittle a student with mental retardation by mocking and intimidating him so he does not participate in class.

When disability harassment limits or denies a student's ability to participate in or benefit from an educational institution's programs or activities, the institution must respond effectively. Where the institution learns that disability harassment may have occurred, the institution must investigate the incident(s) promptly and respond appropriately.

Disability harassment also may deny a free appropriate public education

Disability harassment that adversely affects an elementary or secondary student's education may also be a denial of FAPE under the IDEA, as well as Section 504 and Title II. The IDEA was enacted to ensure that recipients of IDEA funds make available to students with disabilities the appropriate special education and related services that enable them to access and benefit from public education. The specific services to be provided a student with a disability are set forth in the student's individualized education program (IEP) which is developed by a team that includes the student's parents, teachers and, where appropriate, the student. Harassment of a student based on disability may decrease the student's ability to benefit from his or her education and amount to a denial of FAPE.

How to prevent and respond to disability harassment

Schools, school districts, colleges, and universities have a legal responsibility to prevent and respond to disability harassment. As a fundamental step, educational institutions must develop and disseminate an official policy statement prohibiting discrimination based on disability and must establish grievance procedures that can be used to address disability harassment. A clear policy serves a preventive purpose by notifying students and staff that disability harassment is unacceptable, violates federal law, and will result in disciplinary action. The responsibility to respond to disability harassment, when it does occur, includes taking prompt and effective action to end the harassment and prevent it from recurring and, where appropriate, remedying the effects on the student who was harassed.

The following measures are ways to both prevent and eliminate harassment:

- Creating a campus environment that is aware of disability concerns and sensitive to disability harassment; weaving these issues into the curriculum or programs outside the classroom.

- Encouraging parents, students, employees, and community members to discuss disability harassment and to report it when they become aware of it.
- Widely publicizing anti-harassment statements and procedures for handling discrimination complaints, because this information makes students and employees aware of what constitutes harassment, that such conduct is prohibited, that the institution will not tolerate such behavior, and that effective action, including disciplinary action, where appropriate, will be taken.
- Providing appropriate, up-to-date, and timely training for staff and students to recognize and handle potential harassment.
- Counseling both person(s) who have been harmed by harassment and person(s) who have been responsible for the harassment of others.
- Implementing monitoring programs to follow up on resolved issues of disability harassment. Regularly assessing and, as appropriate, modifying existing disability harassment policies and procedures for addressing the issue, to ensure effectiveness.

Technical assistance is available

(Former) U.S. Secretary of Education Richard Riley has emphasized the importance of ensuring that schools are safe and free of harassment. Students can not learn in an atmosphere of fear, intimidation, or ridicule. For students with disabilities, harassment can inflict severe harm. Teachers and administrators must take emphatic action to ensure that these students are able to learn in an atmosphere free from harassment.

Disability harassment is preventable and can not be tolerated. Schools, colleges, and universities should address the issue of disability harassment not just when but before incidents occur. As noted above, awareness can be an important element in preventing harassment in the first place.

The Department of Education is committed to working with schools, parents, disability advocacy organizations, and other interested parties to ensure that no student is ever subjected to such conduct, and that where such conduct occurs, prompt and effective action is taken. For more information, you may contact OCR or OSEP through 1-800-USA-LEARN or 1-800-437-0833 for TTY services.

Thank you for your attention to this serious matter.

Norma V. Cantu,

Assistant Secretary for Civil Rights

Judith E. Heumann,

Assistant Secretary for Office of Special Education and Rehabilitative Services www.ed.gov/PressReleases/07-2000
(Note: Both secretaries' terms ended with the Clinton administration).

1 Section 504 provides: "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." 29 U.S.C. § 794(a). See 34 CFR Part 104 (Section 504 implementing regulations).

2 Title II provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. See 28 CFR Part 35 (Title II implementing regulations).

3 The Department of Education's Office for Civil Rights (OCR) has issued policy guidance on discriminatory harassment based on race (see 59 Fed. Reg. 11448 (Mar. 10, 1994), <http://www.ed.gov/offices/OCR/race394.html>) and sex (see 62 Fed Reg. 12034 (Mar. 13, 1997), <http://www.ed.gov/offices/OCR/sexhar00.html>). These policies make clear that school personnel who understand their legal obligations to address harassment are in the best position to recognize and prevent harassment, and to lessen the harm to students if, despite their best efforts, harassment occurs. In addition, OCR recently collaborated with the National Association of Attorneys General (NAAG) to produce a guide to raise awareness of, and provide examples of effective practices for dealing with, hate crimes and harassment in schools, including harassment based on disability. See "Protecting Students from Harassment and Hate Crime, A Guide for Schools," U.S. Department of Education, Office for Civil Rights, and the National Association of Attorneys General (Jan. 1999) (OCR/NAAG Harassment Guide), Appendix A: Sample School Policies. The OCR/NAAG Harassment Guide may be accessed on the internet at <http://www.ed.gov/pubs/Harassment>. These documents are a good resource for understanding the general principle of discriminatory harassment. The policy guidance on sexual harassment will be clarified to explain how OCR's longstanding regulatory requirements continue to apply in this area in light of recent Supreme Court decisions addressing the sexual harassment of students.

4 20 U.S.C. §1400 et seq.

5 34 C.F.R. § 300.660 et seq.

6 For more information regarding the requirements of state and local laws, consult the OCR/NAAG Harassment Guide, cited in footnote 3 above.

7 Appropriate classroom discipline is permissible, generally, if it is of a type that is applied to all students or is consistent with the Individuals with Disabilities Education Act (IDEA) and Section 504, including the student's Individualized Education Program or Section 504 plan.

8 Section 504 (at 34 CFR § 104.7) and Title II (at 28 CFR § 35.107(a)) require that institutions have published internal policies and grievance procedures to address issues of discrimination on the basis of disability, which includes disability harassment. While there need not be separate grievance procedures designed specifically for disability harassment, the grievance procedures that are available must be effective in resolving problems of this nature.

How your thyroid works

"A delicate Feedback Mechanism"

Your thyroid gland is a small gland, normally weighing less than one ounce, located in the front of the neck. It is made up of two halves, called lobes, that lie along the windpipe (trachea) and are joined together by a narrow band of thyroid tissue, known as the isthmus.

The thyroid is situated just below your "Adams apple" or larynx. During development (inside the womb) the thyroid gland originates in the back of the tongue, but it normally migrates to the front of the neck before birth. Sometimes it fails to migrate properly and is located high in the neck or even in the back of the tongue (lingual thyroid) This is very rare. At other times it may migrate too far and ends up in the chest (this is also rare).

The function of the thyroid gland is to take iodine, found in many foods, and convert it into thyroid hormones: thyroxine (T4) and triiodothyronine (T3). Thyroid cells are the only cells in the body which can absorb iodine. These cells combine iodine and the amino acid **tyrosine** to make T3 and T4. T3 and T4 are then released into the blood stream and are transported throughout the body where they control metabolism (conversion of oxygen and calories to energy).

Every cell in the body depends upon thyroid hormones for regulation of their metabolism. The normal thyroid gland produces about 80% T4 and about 20% T3, however, T3 possesses about four times the hormone "strength" as T4.

The thyroid gland is under the control of the pituitary gland, a small gland the size of a peanut at the base of the brain. When the **level of thyroid hormones (T3 & T4)** drops too low, the pituitary gland produces **Thyroid Stimulating Hormone (TSH)** which stimulates the thyroid gland to produce more hormones. Under the influence of TSH, the thyroid will manufacture and secrete T3 and T4 thereby raising their blood levels. The pituitary senses this and responds by decreasing its TSH production. One can imagine the thyroid gland as a furnace and the pituitary gland as the thermostat. Thyroid hormones are like heat. When the heat gets back to the thermostat, it turns the thermostat off. As the room cools (the thyroid hormone levels drop), the thermostat turns back on (TSH increases) and the furnace produces more heat (thyroid hormones).

The pituitary gland itself is regulated by another gland, known as the hypothalamus. The hypothalamus is part of the brain and produces **TSH Releasing Hormone (TRH)** which tells the pituitary gland to stimulate the thyroid gland (release TSH). One might imagine the hypothalamus as the person who regulates the thermostat since it tells the pituitary gland at what level the thyroid should be set

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Hypothyroidism

Part 1: Introduction, Causes, Symptoms

Hypothyroidism is a condition in which the body lacks sufficient thyroid hormone. Since the main purpose of thyroid hormone is to "run the body's metabolism", it is understandable that people with this condition will have symptoms associated with a slow metabolism. Over five million Americans have this common medical condition. In fact, as many as ten percent of women may have some degree of thyroid hormone deficiency. Hypothyroidism is more common than you would believe...and, millions of people are currently hypothyroid and don't know it!

There are two fairly common causes of hypothyroidism. **The first is a result of previous** (or currently ongoing) **inflammation of the thyroid gland** which leaves a large percentage of the cells of the thyroid damaged (or dead) and incapable of producing sufficient hormone. The most common cause of thyroid gland failure is called **autoimmune thyroiditis** (also called Hashimoto's thyroiditis), a form of thyroid inflammation caused by the patient's own immune system.

The second major cause is the broad category of "medical treatments". As noted on a number of our other pages, the treatment of many thyroid conditions warrants **surgical removal** of a portion or all of the thyroid gland. If the total mass of thyroid producing cells left within the body are not enough to meet the needs of the body, the patient will develop hypothyroidism. Remember, this is often the goal of the surgery as seen in surgery for thyroid cancer. But at other times, the surgery will be to remove a worrisome nodule, leaving half of the thyroid in the neck undisturbed. Sometimes (often), this remaining thyroid lobe and isthmus will produce enough hormone to meet the demands of the body. For other patients, however, it may become apparent years later that the remaining thyroid just can't quite keep up with demand. Similarly, goiters and some other thyroid conditions can be treated with **radioactive iodine therapy**. The aim of the radioactive iodine therapy (for benign conditions) is to kill a portion of the thyroid to [1] prevent goiters from growing larger, or [2] producing too **much** hormone (hyperthyroidism). Occasionally, (often?) the result of radioactive iodine treatment will be that too many cells are damaged so the patient often becomes hypothyroid a year or two later. This is O.K. and usually greatly preferred over the original problem. There are several other **rare causes of hypothyroidism**, of them being a completely "normal" thyroid gland which is not making enough hormone because of a problem in the pituitary gland. If the pituitary does not produce enough Thyroid Stimulating Hormone (TSH) then the thyroid simply does not have the "signal" to make hormone, so it doesn't.

Symptoms of hypothyroidism

- *Fatigue*
- *Weakness*
- *Weight gain or increased difficulty losing weight*
- *Coarse, dry hair*
- *Dry, rough pale skin*
- *Hair loss*
- *Cold intolerance (can't tolerate the cold like those around you)*
- *Muscle cramps and frequent muscle aches*
- *Constipation*
- *Depression*
- *Irritability*
- *Memory loss*
- *Abnormal menstrual cycles*
- *Decreased libido*

Each individual patient will have any number of these symptoms which will vary with the severity of the thyroid hormone deficiency and the length of time the body has been deprived of the proper amount of hormone. Some patients will have one of these symptoms as their main complaint, while another will not have that problem at all and will be suffering from a different symptom. Most will have a combination of a number of these symptoms. Occasionally, some patients with hypothyroidism have no symptoms at all, or they are just so subtle that they go unnoticed. **Note: Although this may sound obvious, if you have these symptoms, you need to discuss them with your doctor and probably seek the skills of an endocrinologist.** If you have already been diagnosed and treated for hypothyroidism and you continue to have any or all of these symptoms, you need to discuss it with your physician. Although treatment of hypothyroidism can be quite easy in some individuals, others will have a difficult time finding the right type and amount of replacement thyroid hormone

Potential dangers of hypothyroidism

Because the body is expecting a certain amount of thyroid hormone the pituitary will make additional thyroid-stimulating-hormone (TSH) in an attempt to entice the thyroid to produce more hormone. This constant bombardment with high levels of TSH may cause the thyroid gland to become enlarged and form a goiter (termed a "compensatory goiter"). Our goiter page goes into this topic in detail, and outlines that a deficiency of thyroid hormone is a common cause of goiter formation. Left untreated, the symptoms of hypothyroidism will usually progress. Rarely, complications can result in severe life-threatening depression, heart failure or coma. Hypothyroidism can often be diagnosed with a simple blood test. In some persons, however, its not so simple and more detailed tests are needed. Most importantly, a good relationship with a good endocrinologist will almost surely be needed.

Hypothyroidism is completely treatable in many patients

simply by taking a small pill once a day! Once again, however, we have made a simplified statement and its not always so easy. There are several types of thyroid hormone preparations and one type of medicine will not be the best therapy for all patients. Many factors will go into the treatment of hypothyroidism and it is different for everybody. Copyright © 1997, 1998. Endocrine Web Inc. All rights reserved

Part 2: Diagnosis and Treatments

Since hypothyroidism is caused by too little thyroid hormone secreted by the thyroid, the diagnosis is based almost exclusively upon measuring the amount of thyroid hormone in the blood. There are normal ranges which have been calculated by computers which measured these hormones in tens of thousands of people. If your hormone levels fall below the normal range, that is consistent with hypothyroidism. These tests are very accurate and reliable and are so routine that they are available to everybody. However, its not always so simple...keep reading.

The idea is to measure blood levels of T4 and TSH. In the typical person with an under-active thyroid gland, the blood level of T4 (the main thyroid hormone) will be low, while the TSH level will be high. This means that the thyroid is not making enough hormone and the pituitary recognizes it and is responding appropriately by making more Thyroid Stimulating Hormone (TSH) in an attempt to force more hormone production out of the thyroid. In the more rare case of hypothyroidism due to pituitary failure, the thyroid hormone T4 will be low, but the TSH level will also be low. The thyroid is behaving "appropriately" under these conditions because it can only make hormone in response to TSH signals from the pituitary. Since the pituitary is not making enough TSH, then the thyroid will never make enough T4. The real question in this situation is what is wrong with the pituitary? But in the typical and most common form of hypothyroidism, the main thyroid hormone T4 is low, and the TSH level is high.

The next question is: When is low too low, and when is high too high? Blood levels have "normal" ranges, but other factors need to be taken into account as well, such as the presence or absence of symptoms. You should discuss your levels with your doctor so you can interpret how they are helping (or not?) fix your problems. **Oh, if only it were this simple all the time!** Although the majority of individuals with hypothyroidism will be easy to diagnose with these simple blood tests, many millions will have this disease in mild to moderate forms which are more difficult to diagnose. The solution for these people is more complex and this is due to several factors. First we must realize that not all patients with hypothyroidism are the same. There are many degrees of this disease from very severe to very mild. Additionally, and very importantly, we cannot always predict just how bad (or good) an individual patient will feel just by examining his or her thyroid hormone levels. In other words, some patients with very "mild" deviations in their thyroid laboratory test results will feel just fine while others will be quite symptomatic. The degree of thyroid abnormalities often, but **NOT ALWAYS**, will correlate with the degree of symptoms. It is important for both you and your physician to keep this in mind since **the goal is not necessarily to make the lab tests go into the normal range, but to make you feel better as well!** We must also keep in mind that even the "normal" thyroid hormone levels in the blood have a fairly large

range, so even if a patient is in the "normal" range, it may not be the normal level for them.

For the majority of patients with hypothyroidism, taking some form of thyroid hormone replacement (synthetic or natural, pill or liquid, etc) will make the "thyroid function tests" return to the normal range, AND, this is accompanied by a general improvement in symptoms making the patient feel better. This does not happen to all individuals, however, and for these patients it is very important to find an endocrinologist who will listen and be sympathetic. Because most patients will be improved (or made completely better) when sufficient thyroid hormone is provided on a daily basis to make the hormone levels in the blood come into the normal range, physicians will often will rely on test results to determine when a patient is on the appropriate dose and therefore doing well. Remember, these tests have a wide normal range.

Find a doctor who helps make you FEEL better, not just make your labs better because once given this diagnosis, you are likely to carry it for a long, long time. There is more than one drug, there is more than one lab test, and there is a "just right" doctor for everybody.

The following are commonly used thyroid tests

Measurement of Serum Thyroid Hormones: T4 by RIA. T4 by RIA (radioimmunoassay) is the most used thyroid test of all. It is frequently referred to as a T7 which means that a resin T3 uptake (RT3u) has been done to correct for certain medications such as birth control pills, other hormones, seizure medication, cardiac drugs, or even aspirin that may alter the routine T4 test. The T4 **reflects the amount of thyroxine in the blood.** If the patient does not take any type of thyroid medication, this **test is usually a good measure of thyroid function.**

Measurement of Serum Thyroid Hormones: T3 by RIA. As stated on our thyroid hormone production page, thyroxine (T4) represents 80% of the thyroid hormone produced by the normal gland and generally represents the overall function of the gland. **The other 20% is triiodothyronine measured as T3 by RIA.** Sometimes the diseased thyroid gland will start producing very high levels of T3 but still produce normal levels of T4. Therefore measurement of both hormones provides an even more accurate evaluation of thyroid function.

Thyroid Binding Globulin. Most of the thyroid hormones in the blood are attached to a protein called thyroid binding globulin (TBG). If there is an excess or deficiency of this protein it alters the T4 or T3 **measurement** but does not affect the **action** of the hormone. If a patient appears to have normal thyroid function, but an unexplained high or low T4, or T3, it may be due to an increase or decrease of TBG. Direct measurement of TBG can be done and will explain the abnormal value. Excess TBG or low levels of TBG are found in some families as an hereditary trait. It causes no problem except falsely elevating or lowering the T4 level. These people are frequently misdiagnosed as being hyperthyroid or hypothyroid, but they have no thyroid problem and need no treatment.

Measurement of Pituitary Production of TSH. Pituitary production of TSH is measured by a method referred to as IRMA

(immunoradiometric assay). Normally, low levels (less than 5 units) of TSH are sufficient to keep the normal thyroid gland functioning properly. When the thyroid gland becomes inefficient such as in early hypothyroidism, the TSH becomes elevated even though the T4 and T3 may still be within the "normal" range. **This rise in TSH represents the pituitary gland's response to a drop in circulating thyroid hormone; it is usually the first indication of thyroid gland failure.** Since TSH is normally low when the thyroid gland is functioning properly, the failure of TSH to rise when circulating thyroid hormones are low is an indication of impaired pituitary function. The new "sensitive" TSH test will show very low levels of TSH when the thyroid is overactive (as a normal response of the pituitary to try to decrease thyroid stimulation). **Interpretations of the TSH level depends upon the level of thyroid hormone;** therefore, the TSH is usually used in combination with other thyroid tests such as the T4 RIA and T3 RIA.

TRH Test. In normal people TSH secretion from the pituitary can be increased by giving a shot containing TSH Releasing Hormone (TRH...the hormone released by the hypothalamus which tells the pituitary to produce TSH). A baseline TSH of 5 or less usually goes up to 10-20 after giving an injection of TRH. Patients with too much thyroid hormone (thyroxine or triiodothyronine) will not show a rise in TSH when given TRH. This "TRH test" is presently the most sensitive test in detecting early hyperthyroidism. Patients who show too much response to TRH (TSH rises greater than 40) may be hypothyroid. This test is also used in cancer patients who are taking thyroid replacement to see if they are on sufficient medication. It is sometimes used to measure if the pituitary gland is functioning. **The new "sensitive" TSH test (above) has eliminated the necessity of performing a TRH test in most clinical situations.**

Iodine Uptake Scan. A means of measuring thyroid function is to measure how much iodine is taken up by the thyroid gland (RAI uptake). Remember, cells of the thyroid normally absorb iodine from our blood stream (obtained from foods we eat) and use it to make thyroid hormone (described on our thyroid function page). Hypothyroid patients usually take up too little iodine and hyperthyroid patients take up too much iodine. The test is performed by giving a dose of radioactive iodine on an empty stomach. The iodine is concentrated in the thyroid gland or excreted in the urine over the next few hours. The amount of iodine that goes into the thyroid gland can be measured by a "Thyroid Uptake". Of course, patients who are taking thyroid medication will not take up as much iodine in their thyroid gland because their own thyroid gland is turned off and is not functioning. At other times the gland will concentrate iodine normally but will be unable to convert the iodine into thyroid hormone; therefore, interpretation of the iodine uptake is usually done in conjunction with blood tests.

Thyroid Scan. Taking a "picture" of how well the thyroid gland is functioning requires giving a radioisotope to the patient and letting the thyroid gland concentrate the isotope (just like the iodine uptake scan above). **Therefore, it is usually done at the same time that the iodine uptake test is performed.**

.For a more detailed explanation of thyroid scans, please see the information at www.endocrineweb.com

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Treatment of Hypothyroidism

Hypothyroidism is usually quite easy to treat (for most people)! The easiest and most effective treatment is simply taking a thyroid hormone pill (Levothyroxine) once a day, preferably in the morning. This medication is a pure synthetic form of T4 which is made in a laboratory to be an exact replacement for the T4 that the human thyroid gland normally secretes. It comes in multiple strengths, which means that an appropriate dosage can almost always be found for each patient. The dosage should be re-evaluated and possibly adjusted monthly until the proper level is established. The dose should then be re-evaluated at least annually. If you are on this medication, make sure your physician knows it so he/she can check the levels at least yearly. **Note:** Just like we discussed above, however, this simple approach does not hold true for everybody. Occasionally the correct dosage is a bit difficult to pin-point and therefore you may need an exam and blood tests more frequently. Also, some patients just don't do well on some thyroid medications and will be quite happy on another. For these reasons you should **not** be shy in discussing with your doctor your blood hormone tests, symptoms, how you feel, and the type of medicine you are taking. The goal is to make you feel better, make your body last longer, slow the risk of heart disease and osteoporosis...in addition to making your blood levels normal! Sometimes that's easy. When its not, you need a physician who is willing to spend the time with you that you deserve while you explore different dosages, other types of medications, or alternative diagnoses.

Some patients will notice a slight reduction in symptoms within 1 to 2 weeks, but **the full metabolic response to thyroid hormone therapy is often delayed for a month or two** before the patient feels completely normal. It is important that the correct amount of thyroid hormone is used. Not enough and the patient may have continued fatigue or some of the other symptoms of hypothyroidism. Too high a dose could cause symptoms of nervousness, palpitations or insomnia typical of hyperthyroidism. Some recent studies have suggested that too much thyroid hormone may cause increased calcium loss from bone increasing the patient's risk for osteoporosis. For patients with heart conditions or diseases, an optimal thyroid dose is particularly important. Even a slight excess may increase the patient's risk for heart attack or worsen angina. Some physicians feel that more frequent dose checks and blood hormone levels are appropriate in these patients.

After about one month of treatment, hormone levels are measured in the blood to establish whether the dose of thyroid hormone which the patient is taking is appropriate. We don't want too much given or subtle symptoms of hyperthyroidism could ensue, and little would not alleviate the symptoms completely. Often blood samples are also checked to see if there are antibodies against the thyroid, a sign of autoimmune thyroiditis. Remember, this is the most common cause of hypothyroidism. Once treatment for hypothyroidism has been started, it typically will continue for the patient's life. Therefore, it is of great importance that the diagnosis be firmly established and you have a good relationship with a physician you like and trust. **Synthetic T4 can be safely taken with most other medications.** Patients taking cholestyramine (a compound used to lower blood cholesterol) or

certain medications for seizures should check with their physician about potential interactions. Women taking T4 who become pregnant should feel confident that the medication is exactly what their own thyroid gland would otherwise make. However, they should check with their physician since the T4 dose may have to be adjusted during pregnancy (usually more hormone is needed to meet the increased demands of the mother's new increased metabolism). There are other potential problems with other drugs including iron-containing vitamins. Once again, pregnant women (and all women and men for that matter) taking iron supplements should discuss this with your physician. There are three brand name Levothyroxine tablets now available. You may want to consult You may want to consult with your physician or pharmacist on the most cost effective brand since recent studies suggest that none is better than the other.

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DEPRESSION IN CHILDREN AND ADOLESCENTS

NIH Publication

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Depressive disorders, which include major depressive disorder (unipolar depression), dysthymic disorder (chronic, mild depression), and bipolar disorder (manic-depression), can have far reaching effects on the functioning and adjustment of young people. Among both children and adolescents, depressive disorders confer an increased risk for illness and interpersonal and psychosocial difficulties that persist long after the depressive episode is resolved; in adolescents there is also an increased risk for substance abuse and suicidal behavior 1,2,3. Unfortunately, these disorders often go unrecognized by families and physicians alike. Signs of depressive disorders in young people often are viewed as normal mood swings typical of a particular developmental stage. In addition, health care professionals may be reluctant to prematurely "label" a young person with a mental illness diagnosis. Yet **early diagnosis and treatment of depressive disorders are critical to healthy emotional, social, and behavioral development.**

Although the scientific literature on treatment of children and adolescents with depression is far less extensive than that concerning adults, a number of studies-mostly conducted in the last four to five years-have confirmed the short-term efficacy and safety of treatments for depression in youth. Larger treatment trials are needed to determine which treatments work best for which youngsters, and studies are also needed, however, on how to best incorporate these treatments into primary care practice.

Given the challenging nature of the problem, it is usually advisable to involve a child psychiatrist or psychologist in the evaluation,

diagnosis, and treatment of a child or adolescent in whom depression is suspected.

This fact sheet, prepared by the National Institute of Mental Health (NIMH), the lead Federal agency for research on mental disorders, summarizes some of the latest scientific findings on child and adolescent depression and lists resources where physicians can obtain more information.

Scope of the problem A number of epidemiological studies have reported that up to 2.5 percent of children and up to 8.3 percent of adolescents in the U.S. suffer from depression 4. An NIMH-sponsored study of 9- to 17-year-olds estimates that the prevalence of any depression is more than 6 percent in a 6-month period, with 4.9 percent having major depression 5. In addition, research indicates that depression onset is occurring earlier in life today than in past decades 6. A recently published longitudinal prospective study found that early-onset depression often persists, recurs, and continues into adulthood, and indicates that depression in youth may also predict more severe illness in adult life 3. Depression in young people often co-occurs with other mental disorders, most commonly anxiety, disruptive behavior, or substance abuse disorders, 7 and with physical illnesses, such as diabetes 8.

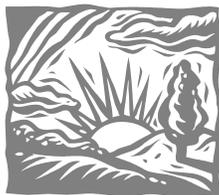
Suicide. Depression in children and adolescents is associated with an increased risk of suicidal behaviors 3,9. This risk may rise, particularly among adolescent boys, if the depression is accompanied by conduct disorder and alcohol or other substance abuse 10. In 1997, suicide was the third leading cause of death in 10- to 24-year-olds 11. NIMH-supported researchers found that among adolescents who develop major depressive disorder, as many as 7 percent may commit suicide in the young adult years 3. Consequently, it is important for doctors and parents to take all threats of suicide seriously.

NIMH researchers are developing and testing various interventions to prevent suicide in children and adolescents. Early diagnosis and treatment, accurate evaluation of suicidal thinking, and limiting young people's access to lethal agents-including firearms 12 and medications-may hold the greatest suicide prevention value.

Clinical Characteristics

The diagnostic criteria and key defining features of major depressive disorder in children and adolescents are the same as they are for adults. However, recognition and diagnosis of the disorder may be more difficult in youth for several reasons. **The way symptoms are expressed varies with the developmental stage of the youngster 1, 2.** In addition, children and young adolescents with depression may have difficulty in properly identifying and describing their internal emotional or mood states. For example, instead of communicating how bad they feel, they may act out and be irritable toward others, which may be interpreted simply as misbehavior or disobedience.

Research has found that parents are even less likely to identify major depression in their adolescents than are the adolescents themselves 13.



Symptoms of major depressive disorder

Common to Adults, Children, and Adolescents [14](#)

- Persistent sad or irritable mood
- Loss of interest in activities once enjoyed
- Significant change in appetite or body weight
- Difficulty sleeping or oversleeping
- Psychomotor agitation or retardation
- Loss of energy
- Feelings of worthlessness or inappropriate guilt
- Difficulty concentrating
- Recurrent thoughts of death or suicide

Five or more of these symptoms must persist for 2 or more weeks before a diagnosis of major depression is indicated

Signs that may be associated with depression in children and adolescents

- Frequent vague, non-specific physical complaints such as headaches, muscle aches, stomachaches or tiredness
- Frequent absences from school or poor performance in school
- Talk of or efforts to run away from home
- Outbursts of shouting, complaining, unexplained irritability, or crying
- Being bored
- Lack of interest in playing with friends
- Alcohol or substance abuse
- Social isolation, poor communication
- Fear of death
- Extreme sensitivity to rejection or failure
- Increased irritability, anger, or hostility
- Reckless behavior
- Difficulty with relationships

While the recovery rate from a single episode of major depression in children and adolescents is quite high [15](#), episodes are likely to recur [16](#). In addition, youth with dysthymic disorder are at risk for developing major depression [17](#). Prompt identification and treatment of depression can reduce its duration and severity and associated functional impairment.

Screening

There are several tools that are useful for screening children and adolescents for possible depression. They include the Children's Depression Inventory (CDI) [18](#) for ages 7 to 17; and, for adolescents, the Beck Depression Inventory (BDI) [19](#) and the Center for Epidemiologic Studies Depression (CES-D) Scale [20](#). When a youngster screens positive on any of these instruments, a comprehensive diagnostic evaluation by a mental health professional is warranted. The evaluation should include interviews with the youth, parents, and when possible, other informants such as teachers and social services personnel.

Risk Factors

In childhood, boys and girls appear to be at equal risk for depressive disorders; but during adolescence, girls are twice as likely as boys to develop depression [4](#). Children who develop major depression are more likely to have a family history of the disorder,

often a parent who experienced depression at an early age, than patients with adolescent- or adult-onset depression [21](#). Adolescents with depression are also likely to have a family history of depression, though the correlation is not as high as it is for children.

Other risk factors include:

- Stress ²²
- Cigarette smoking ²²
- A loss of a parent or loved one ²³
- Break-up of a romantic relationship ²⁴
- Attentional, conduct or learning disorders ²⁵
- Chronic illnesses, such as diabetes ⁸
- Abuse or neglect ²⁶
- Other trauma, including natural disasters ²⁷

Treatment

Treatment for depressive disorders in children and adolescents often involves short-term psychotherapy, medication, or the combination, and targeted interventions involving the home or school environment. **There remains, however, a pressing need for additional research on the effectiveness of psychosocial and pharmacological treatments for depression in youth.** While data from adults indicate the need for maintenance treatment after episode recovery in order to prevent recurrences, the value of such treatment in children and adolescents has yet to be determined through research.

Psychotherapy

Recent research shows that certain types of short-term psychotherapy, particularly cognitive-behavioral therapy (CBT), can help relieve depression in children and adolescents [1,28,29](#). CBT is based on the premise that people with depression have cognitive distortions in their views of themselves, the world, and the future. CBT, designed to be a time-limited therapy, focuses on changing these distortions. An NIMH-supported study that compared different types of psychotherapy for major depression in adolescents found that CBT led to remission in nearly 65 percent of cases, a higher rate than either supportive therapy or family therapy. CBT also resulted in a more rapid treatment response [30](#).

Another specific psychotherapy, interpersonal therapy (IPT), focuses on working through disturbed personal relationships that may contribute to depression. IPT has not been well investigated in youth with depression; however, one controlled study found that IPT led to greater improvement than clinical contact alone [31](#).

Continuing psychotherapy for several months after remission of symptoms may help patients and families consolidate the skills learned during the acute phase of depression, cope with the after effects of the depression, effectively address environmental stressors, and understand how the young person's thoughts and behaviors could contribute to a relapse [1](#).

Medication

Research clearly demonstrates that antidepressant medications, especially when combined with psychotherapy, can be very effective treatments for depressive disorders in adults [32](#). Using medication to treat mental illness in children and adolescents, however, has caused controversy. Many doctors have been

understandably reluctant to treat young people with psychotropic medications because, until fairly recently, little evidence was available about the safety and efficacy of these drugs in youth.

In the last few years, however, researchers have been able to conduct randomized, placebo-controlled studies with children and adolescents. Some of the newer antidepressant medications, specifically the selective serotonin reuptake inhibitors (SSRIs), have been shown to be safe and efficacious for the short-term treatment of severe and persistent depression in young people, although large scale studies in clinical populations are still needed. So far, there are two controlled studies showing efficacy of fluoxetine and paroxetine, respectively [33,34](#). It is important to note that available studies do not support the efficacy of tricyclic antidepressants (TCAs) for depression in youth [35,36](#).

Medication as a first-line course of treatment should be considered for children and adolescents with severe symptoms that would prevent effective psychotherapy, those who are unable to undergo psychotherapy, those with psychosis, and those with chronic or recurrent episodes. Following remission of symptoms, continuation treatment with medication and/or psychotherapy for at least several months may be recommended by the psychiatrist, given the high risk of relapse and recurrence of depression. Discontinuation of medications, as appropriate, should be done gradually over 6 weeks or longer [1](#).

NIMH has initiated a large-scale, controlled clinical trial at 10 sites across the U.S. to compare the long-term effectiveness of fluoxetine, CBT, and the combination of these interventions for treatment of depression in adolescents. More information about this trial, called the Treatment of Adolescents with Depression Study, and others can be found through the Clinical Trials page of the NIMH web site <http://www.nimh.nih.gov/studies/index.cfm>.

Talking with parents

It is very important for parents to understand their child's depression and the treatments that may be prescribed. Physicians can help by talking with parents about their questions or concerns, reinforcing that depression in youth is not uncommon, and reassuring them that appropriate treatment with psychotherapy, medication, or the combination can lead to improved functioning at school, with peers, and at home with family. In addition, referring the youth and family to a mental health professional and to the information resources listed at the back of this publication can help to enhance recovery.

Other types of depression in children and adolescents

Bipolar Disorder

Although rare in young children, bipolar disorder-also known as manic-depressive illness-can appear in both children and adolescents [37](#). Bipolar disorder, which involves unusual shifts in mood, energy, and functioning, may begin with either manic, depressive, or mixed manic and depressive symptoms. It is more likely to affect the children of parents who have the disorder. Twenty to 40 percent of adolescents with major depression develop

bipolar disorder within 5 years after depression onset [4](#).

Existing evidence indicates that bipolar disorder beginning in childhood or early adolescence may be a different, possibly more severe form of the illness than older adolescent- and adult-onset bipolar disorder [38](#). When the illness begins before or soon after puberty, it is often characterized by a continuous, rapid-cycling, irritable, and mixed symptom state that may co-occur with disruptive behavior disorders, particularly attention deficit hyperactivity disorder (ADHD) or conduct disorder (CD), or may have features of these disorders as initial symptoms. In contrast, later adolescent- or adult-onset bipolar disorder tends to begin suddenly, often with a classic manic episode, and to have a more episodic pattern with relatively stable periods between episodes. There is also less co-occurring ADHD or CD among those with later onset illness.

Bipolar Disorder: Manic Symptoms [14,37](#)

- **Severe changes in mood-either extremely irritable or overly silly and elated**
- **Overly-inflated self-esteem; grandiosity**
- **Increased energy**
- **Decreased need for sleep-able to go with very little or no sleep for days without tiring**
- **Increased talking-talks too much, too fast; changes topics too quickly; cannot be interrupted**
- **Distractibility-attention moves constantly from one thing to the next**
- **Hypersexuality-increased sexual thoughts, feelings, or behaviors; use of explicit sexual language**
- **Increased goal-directed activity or physical agitation**
- **Disregard of risk-excessive involvement in risky behaviors or activities**

A child or adolescent who appears to be depressed and exhibits ADHD-like symptoms that are very severe, with excessive temper outbursts and mood changes, should be evaluated by a psychiatrist or psychologist with experience in bipolar disorder, particularly if there is a family history of the illness.

This evaluation is especially important since psychostimulant medications, often prescribed for ADHD, may worsen manic symptoms. There is also limited evidence suggesting that some of the symptoms of ADHD may be a forerunner of full-blown mania [38](#).

The essential treatment of bipolar disorder in adults involves the use of appropriate doses of mood stabilizing medications, typically lithium and/or valproate, which are often very effective for controlling mania and preventing recurrences of manic and depressive episodes. Treatment of children and adolescents diagnosed with bipolar disorder is based mainly on experience with adults, since as yet there is very limited data on the safety and efficacy of mood stabilizing medications in youth. Researchers currently are evaluating both pharmacological and psychosocial interventions for bipolar disorder in young people.

Bipolar Disorder:

A Warning About Antidepressants and Psychostimulants

Using antidepressant medication to treat depression in a person who has bipolar disorder may induce manic symptoms if it is taken without a mood stabilizer, such as lithium or valproate **37**. In addition, using psychostimulant medications to treat ADHD or ADHD-like symptoms in a child or adolescent with bipolar disorder may worsen manic symptoms. While it can be hard to determine which young patients will become manic, there is a greater likelihood among children and adolescents who have a family history of bipolar disorder. If manic symptoms develop or markedly worsen during antidepressant or stimulant use, a child psychiatrist should be consulted, and treatment for bipolar disorder should be considered. Physicians should be aware of the signs and symptoms of mania so that they can educate families on how to recognize these and report them immediately.

Valproate Use

According to studies conducted in Finland in patients with epilepsy, valproate may increase testosterone levels in teenage girls and produce polycystic ovary syndrome in women who began taking the medication before age 20 **39**. Increased testosterone can lead to polycystic ovary syndrome with irregular or absent menses, obesity, and abnormal growth of hair. Therefore, young female patients prescribed valproate should be monitored carefully.

Dysthymic disorder (or dysthymia)

This less severe yet typically more chronic form of depression is diagnosed when depressed mood persists for at least one year in children or adolescents and is accompanied by at least two other symptoms of major depression **14**. Dysthymia is associated with an increased risk for developing major depressive disorder, bipolar disorder, and substance abuse **4,17**. Treatment of dysthymia may prevent the deterioration to more severe illness **1**. If dysthymia is suspected in a young patient, referral to a mental health specialist is indicated for a comprehensive diagnostic evaluation and appropriate treatment

Information Resources

National Institute of Mental Health

Office of Communications and Public Liaison

Information Resources and Inquiries Branch

6001 Executive Boulevard,

Rm. 8184, MSC 9663

Bethesda, MD 20892-9663

(301) 443-4513

Mental Health FAX 4U: (301) 443-5158

E-mail: nimhinfo@nih.gov

NIMH home page: www.nimh.nih.gov

American Academy of Child and Adolescent Psychiatry

3615 Wisconsin Avenue, N.W.

Washington, DC 20016

(202) 966-7300

www.aacap.org

American Psychiatric Association

1400 K Street, N.W.

Washington, DC 20005

(202) 682-6000

www.psych.org

American Psychological Association

750 First Street, N.E.

Washington, DC 20002

(202) 336-5500

www.apa.org

Child & Adolescent Bipolar Foundation

1187 Willmette Avenue, PMB #331

Willmette, IL 60091

(847) 256-8525

www.bpkids.org

National Alliance for the Mentally Ill

Colonial Place Three

2107 Wilson Blvd., Suite 300

Arlington, VA 22201-3042

(800) 950-NAMI (-6264)

www.nami.org

National Depressive and Manic-Depressive Association

730 N. Franklin Street, Suite 501

Chicago, IL 60610-3526

(800) 826-3632

www.ndmda.org

National Mental Health Association

1021 Prince Street

Alexandria, VA 22314

(800) 969-NMHA (-6642)

www.nmha.org

National Institutes of Health,

National Library of Medicine's clinical trials database www.clinicaltrials.gov

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Your Child and Medication

From The National Institute of Mental Health

One in ten of America's children has an emotional disturbance such as attention deficit hyperactivity disorder, depression or anxiety, that can cause unhappiness for the child and problems at home, at play, and at school. Many of these children will be taken by their parents to their family physician or pediatrician, or, in many cases, a specialist in child mental health. The child will be carefully evaluated and may begin some type of therapy. There are many treatment options available. Choosing the right treatment for your child is very important. Each child is different. At times, psychotherapies, behavioral strategies, and family support may be very effective. In some cases, medications are needed to help the child become more able to cope with everyday activities.

If you are planning to have a doctor see your child, you should share a record of any of your child's medical problems, any medications your child is taking, including over-the-counter medications or vitamin and herbal supplements, and any allergic reactions your child has suffered. If a medication is prescribed for your child, there are certain questions you should ask. It will be helpful to take notes as it is easy to forget exactly what the doctor says.

- What is the name of the medication and how will it help my child?
- Is the medicine available in both brand-name and generic versions, and is it all right to use the less expensive (generic) medication?
- What is the name of the generic version?
- Is it all right to switch among brands, or between brand-name and generic forms?
- What is the proper dosage for my child? Is the dose likely to change as he or she grows?
- What if my child has a problem with the pill or capsule? Is it available in a chewable tablet or liquid form?
- How many times a day must the medicine be given? Should it be taken with meals, or on an empty stomach? Should the school give the medication during the day?
- How long must my child take this medication? If it is discontinued, should it be done all at once or slowly?
- Will my child be monitored while on this medication and, if so, by whom?
- Should my child have any laboratory tests before taking this medication? Will it be necessary to have blood levels checked or have other laboratory tests during the time my child is taking this medication?
- Should my child avoid certain foods, other medications, or activities while using this medication?
- Are there possible side effects? If I notice a side effect—such as unusual sleepiness, agitation, fatigue, hand tremors—should I notify the doctor at once?
- What if my child misses a dose? Spits it up?
- How well established and accepted is the use of this medication in children or adolescents?

You may think of other questions. Don't be afraid to ask.

When you have the prescription filled, be sure the pharmacist gives you a flyer describing the medication, how it should be taken, and any possible side effects it may have. The label on the medication will have lots of information. Read the label carefully before giving the medication to your child. The label will give the name of the pharmacy, its telephone number, the name of the medication, the dosage, and when it should be taken. It will also tell you how many times the medication can be refilled.

If you want to learn more about your child's medication, you will find helpful books at your public library, or the reference librarian can show you how to look up the medication in the Physicians' Desk Reference (PDR). While a great deal of information about mental disorders and their treatment in children is available on the Internet, care is required to distinguish fact from opinion.

What does "off-label" mean?

Based on clinical experience and medication knowledge, a physician may prescribe to young children a medication that has been approved by the U.S. Food and Drug Administration (FDA) for use in adults or older children. This use of the medication is called "off-label." Most medications prescribed for child mental disorders, including many of the newer medications that are proving helpful, are prescribed off-label because only a few of them have been systematically studied for safety and efficacy in children. Medications that have not undergone such testing are dispensed with the statement that "safety and efficacy have not been established in pediatric patients." The FDA has been urging that products be appropriately studied in children and has offered incentives to drug manufacturers to carry out such testing. The National Institutes of Health and the FDA are examining the issue of medication research in children and are developing new research approaches.

Help your child take medication safely

Be sure the doctor knows all medications—including over-the-counter medications and herbal and vitamin supplements—that your child takes.

- Read the label before opening the bottle. Make sure you are giving the proper dosage. If the medication is liquid, use a special measure—a cup, a teaspoon, a medicine dropper, or a syringe. Often a measure comes with the medicine. If not, ask your pharmacist which measure is most suitable to use with the medication your child is taking.
- Always use child-resistant caps and store all medications in a safe place.
- Never decide to increase or decrease the dosage or stop the medication without consulting the doctor.
- Don't give medication prescribed for one child to another child, even if it appears to be the same problem.
- Keep a chart and mark it each time the child takes the medication. It is easy to forget.

*PARENT PERSPECTIVE***"Something isn't right..."**

by Susan Johnson

I spoke these words often when talking about my son, born with XXY, referring to phenomena I saw that did not meet my expectations of normalcy. His differences were not easily discernible; no physical attributes gave merit to my feelings. His masked difference with its manifestations led me to make conclusions and inferences based upon my own frame of reference. For me, I knew what I knew. What did not "fit" my knowing led me to conclude that something was amiss and had to be fixed. Otherwise, my son would not be like the rest of the world or at least like the world that I knew.

Why did I act in the way I did? More important, how did my actions affect my son? My knowledge and experiences make new situations familiar and comfortable. When faced with situations that do not conform to what I know, I become uncomfortable. As the comfort level decreases, I adjust to the situation by forcing what is creating discomfort into my frame of reference, my history of experiences. If the observed behavior does not fit my experiences, then I label it "not right" or "wrong" and this labeling process allows my comfort level to rise. The label categorizes it in a safe way, by allowing me to perceive it without it threatening my sense of reality.

I do not believe I differ much from others in feeling and reacting this way. In a moment's time, a person views something, relates it to previous knowledge, **see page 20**

cont. from page 19 interprets it to fit personal reality, labels it, and decides to accept or reject it. People do this hundreds of times a day without giving much thought to the process.

This process often results in people perceiving themselves through the eyes of others as "not right" when, indeed, they are very "right." They may differ from another's reality or experience. Nevertheless, they are right according to how they were formed and how they developed.

To demonstrate this phenomenon, think about this scenario. You drive your car along a city street and as you near an intersection, an apparatus, hanging from wires stretched across the intersection, is beaming colors at you. You see three lights on this apparatus. The top light is red, the middle yellow, and the bottom green. The top light shines brighter than the other two. You see the light (red), its position on the signal, and the fact that you are approaching an intersection. What do you do? You take your foot off the accelerator and place it on the brake, stopping your car. Why? You stop because you have associated a red light at the top of an apparatus-- at an intersection-- with a specified behavior --stopping your car. You learned this behavior to operate a car safely on the streets shared with other drivers in cars. You know that failure to do so causes accidents or a traffic ticket. Both of these consequences are undesirable; therefore, you accept this norm and comply.

Do you stop if you are the only car at the intersection?

Probably. Most people do. Do you stop if you are the only car and it is in the middle of the night? Again, probably you do as most would do. Why? Because we associate a behavior with a certain stimulus, accept it as "right," and incorporate it into our frame of reference.



What would happen if, one morning, we drove to work and all the lights were switched? The green was now on top, then the yellow, and finally the red on the bottom. More than likely, we would react to the color, not the position of the light, but our compliance would make us feel uncomfortable because the situation was "not right." If the change were permanent, we would adjust our thinking and accept it because red still meant stop, yellow--caution, and green--go on. In time, this new situation would become totally accepted into our mode of thinking. The unfamiliar positioning of the lights had elements of the familiar; therefore, this new learning is incorporated in our thinking and becomes acceptable, reducing our discomfort. This familiarity allows us to adapt to the change and adopt it into our lives.

The positioning of lights in a traffic signal is not inherently right. We make it right because we say it is so. We conform our behavior. We accept the reality and make it part of our lives.

We do the same thing when we think, talk, and act and perceive others thinking, talking and acting. Our past experiences shape our perceptions of others and influence our level of comfort with their behavior. If we are raised to think, talk, and act in certain ways, then other ways will make us feel uncomfortable. We respond to this discomfort by categorizing and labeling. Our comfort level rises when we label the unfamiliar as "not right."

The difference between human behavior and the new traffic signal is that with human behavior there is no one standard. There are accepted developmental milestones, culturally acceptable behaviors and customs, rules of protocol and social interaction; yet, by the very nature of all that is human, there is variation between individuals and groups of individuals. The accepted norms, though, are so ingrained into our being that any deviation makes that a difference perceived as "not right."

This discussion illustrates how caring people often create an atmosphere of alienation by the choice of language when viewing another person. Who is to really decide what is "right" when discussing human behavior? Expressing differences in terms of right or wrong creates a judgmental atmosphere in which people may perceive themselves to be patronized or talked down to. To continually hear that one's way of thinking, talking, acting is not right, can mislead an individual to believe he is "broken" and in need of "fixing."

So, how can discussions of differences take place to further understanding and acceptance? A discussion based upon mutual respect is one way. When discussing my son's language development, should I say that he is "delayed in expressive language?" Should I say that his "inferential comprehension was lower than it should be?" What would be a better way to express these issues?

We can begin by rethinking the language we use, the labeling we do, the importance we place on doing things our way. We must

tell to our sons and others with XXY that they have qualities and strengths that they can develop. We must validate that they bring different perspectives to the traditional world. Encouraging the growth of their strengths will enable them to live full and successful lives -- a goal every parent has for his/her child. The genetic signature plays no role in this desire nor does it separate our children and ourselves from any other child and parent.

As a parent of a son with XXY, I want to provide support and encouragement to him and others with XXY. I finally understand that this desire does not begin by labeling behavior to ease my own discomfort. It starts with entering a dialogue with my son to identify what he wants, not what I perceive he needs.

The traffic signal creates a safe place for complex human interaction. Our association should create a place for listening to the XXY adults and hearing what they want AAKSIS to deliver. AAKSIS can provide the environment to explore these issues with open dialogue and mutual respect.