

Types of Disability II

In this unit, we are going to talk about five more of the underlying conditions that cause or contribute to people having a disability.

[Click here to read the directions for the activities](#) you are supposed to do to demonstrate completion of each of the sections linked to this page. The product, a notebook entry, is the same for every topic.

Now that you know something about the process of identifying educationally relevant disabilities, you are ready to proceed to learning a little bit more about specific diagnoses. On this web site the emphasis is on the students who are likely to be classified as having a functional mental disability, the people you are encountering in peer tutoring. Nevertheless, remember the presence of one of these diagnoses does not mean a person automatically has a severe disability. While anyone described here would clearly have an impairment or disorder, to use the language of the World Health Organization, their actual disability could be mild, severe, or not adversely affect their educational performance.

The point is to always see the person first!

On the links in this unit, you will have the opportunity to find out more about the following conditions:

1. [Seizure Disorder](#)
2. [Multiple Disability](#)
3. [Sensory Disability](#)
4. [Spina Bifida](#)
5. [Syndrome Disorders and Rare Conditions.](#)

Direction for Activities:

The structure of each of these topics is similar. You will review at least the following three types of information:

- 1) fact sheets or frequently asked questions lists that present basic information about the condition;
- 2) links to at least one major organization concerned with people who have this conditions; and
- 3) at least one story about a person who has the condition.

In some cases, there will be other links that you will be asked to examine because of their relevance to the topic.

What are you expected to know when you finish each of these topics? In other words, what will we be on the quizzes?

When you finish this unit, we want you to have an accurate understanding of the conditions. We are not trying to turn you into experts or junior professionals, but that does not mean we do not expect you to remember specific information. As in so many fields, an accurate understanding of disability requires knowing some facts—it is not all a matter of opinion.

Your assignment for each of these units is to keep a notebook in which you will answer the following questions. When you are done with this unit, show your notebook to your teacher. You should be ready for the quiz. The topics in your notebook should be:

1. What are the essential elements in the **definition** of this condition? (Can you explain this condition to your parents or classmates in a way they would understand it?)
2. How is it **different** from other conditions? (What is unique about this condition; for example, how is spina bifida different from cerebral palsy?)
3. Are there different **forms** of this condition? (What kind of variation will you see in people with this condition—do professionals have names or terms they use to describe this variation?)
4. What do we know about what **causes** this condition?
5. What are the **difficulties** a person with this condition is likely to encounter in school and in day-to-day life in the

community?

6. What are some **supports** that will assist a person with this condition? (How would you answer someone if that person asked you to offer some ideas about things they could do to help a person with this condition?)
7. What is at least one major **organization** that is a good source of information about this condition?
8. Can you list at least three major **issues** (problems, controversies, etc) related to this condition?
9. Finally, what are the major **myths or misconceptions** (list at least 3) that people have about people with this condition and what are some things you could do to show others the error of their beliefs?

Seizure Disorder

About 2,000,000 Americans have a seizure disorder. It is something that any of us could encounter or experience at any time. Therefore, we all should really know something about this group of conditions. We emphasize it here because the students with whom you are working as a peer tutor, because of the neurological basis of some of their conditions, are more likely to have seizure disorder than the average student. Make sure your notebook material is accurate; people with seizure disorder have too long been the victim of misinformation and prejudice.

1. **Epilepsy Fact Sheet** from NICHCY provides basic information on epilepsy on this fact sheet. <http://www.nichcy.org/pubs/factshe/fs6txt.htm>
2. **Epilepsy Foundation** is a national organization, founded in 1968 as the Epilepsy Foundation of America. The only such organization wholly dedicated to the welfare of people with epilepsy. Its mission is simple: to work for children and adults affected by seizures through research, education, advocacy and service. Look at the section entitled the “**answer place**” for up to date information <http://www.efa.org/>
3. **BLURT** is a website for teens with epilepsy. If you are on the Epilepsy Foundation home page, click on the link on the right side of the homepage to enter the special section for teenagers <http://www.efa.org/blurt> . While there, take some time to play the game “**spellbound**.”
4. A neurologist provides specific direction on “What to do when you see someone having a seizure” <http://www.northeastrehab.com/Articles/seizurefaq.htm#todo>
5. **Alison's Website**. Alison is a beautiful girl who is full of life, and hasn't let the results of a rare seizure disorder, called infantile spasms, keep her from enjoying life to its fullest. This site features her story, a picture gallery, related disability links, and resources that interest Alison. <http://www.alisonhigginbotham.com/index.htm>

Additional Resources & Stories

- **Epilepsy** from TeensHealth! TeensHealth was created for teens looking for honest, accurate information and advice about health, relationships, and growing up. Created by The Nemours Foundation's for Children's Health Media, TeensHealth provide teens and families with accurate, up-to-date, and jargon-free health information they can use.
- **Epilepsy facts** on the Epilepsy Canada website presents information in a clear and interesting fashion. : <http://www.epilepsy.ca/eng/sheet.html>
- **The Family Village - Epilepsy / Seizure Disorders** Like all of the links to this group this one provides medical information, a list of contacts, mailing lists and a selection of related links at http://www.familyvillage.wisc.edu/lib_epil.htm
- **Epilepsy and Seizures - Neurologychannel** There are many disorders that cause seizures; epilepsy is only one. Learn about treatment and diagnosis of seizure disorders. <http://www.neurologychannel.com/seizures>
- **Epilepsy Personal Stories** Sarah Blake has developed a wonderful website on physical disabilities titled [growingstrong.org](http://www.growingstrong.org). Here, she shares her personal story and how she has been challenged with physical difficulties since birth. Part of this site also features information on epilepsy and personal stories by those who are challenged with this disability. <http://www.growingstrong.org/epilepsy/exp.html>

Multiple Disabilities

If you think back to the categories of disability listed in the Individuals with Disabilities Education Act, you will recall two “catch-all” categories, multiple disability and deafblindness. These are related. The combination of vision impairment with hearing impairment is obviously a multiple disability. However, the special communication issues presented by “dual sensory impaired” individuals led Congress to make them a separate category. As you will see below, this has led to series of specialized programs being set up for this small but hard to serve population.

In most schools in Kentucky, a significant number of students with whom you will be working as a peer tutor are identified as having multiple disabilities. Most frequently, these will be individual identified as having an intellectual disability and some other disabling condition. This will include students with the most extensive needs, such as physical disability, specialized health needs, and intellectual disability. It is very easy to be overwhelmed by people with complex needs for personal assistance and specialized services. What you need to bring away from this topic is an understanding that the need for this level of support does not change the basic human equation. We all are more the same than we are different. With some people, we need to work a little harder to make a connection and to understand.

As with many of the topics, there is a great deal of information available. However, as in other topics the first five sites should give you the essential information needed to complete your notebook entry. Do not let that stop you from taking some time to look at some of the additional sites and building your understanding.

1. [Severe and/or Multiple Disabilities Fact Sheet](#) NICHCY fact sheet on severe and multiple disabilities.
2. [The Student with Multiple Disability](#) is a chapter from *Creating Opportunities for Students with Intellectual or Multiple Disabilities*, a document from the Saskatchewan Department of Education. This 2001 manual is a resource to assist with educating students with intensive educational needs. This chapter summarizes who this group of students is and the many issues related to meeting their needs. It is long, but presented in a form that will make it easy for you to review it. It contains some material that is already covered in the discussion of other conditions but, remember it all remains relevant to students with **multiple** disabilities.

3. [TASH](#) is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm. The name of the organization requires some explanation.

When TASH was started in 1974, it was called the American Association for the Education of the Severely / Profoundly Handicapped and went by the acronym: AAESPH. In 1980 the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to The Association for Persons with Severe Handicaps in 1983 but the acronym, TASH, continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization, as it did not reflect current values and directions. Probably the best answer to the question: "What does TASH stand for?" is Equity, Diversity, Social Justice and Inclusion!

Explore this site a bit, but be sure to review “[resolutions](#)” to see what this group is about. Under “[values](#),” the resolution “[Who TASH advocates for](#)” has been used as the basis for a working definition of “severe” disability.

4. [Information about Multiple Disability and Deafblindness](#) This web page from the Royal Institute for Deaf and Blind Children in Australia provides a very systematic overview of multiple disability and deafblindness. Each of the discussions provide a definition and examination of causes and a summary of effective intervention. See the links in the upper right section of the page to move between categories, then click on the tabs to move through the topics. Note that while the site is located in Australia, most of the information is from sources in the United States.

5. [Success Stories](#) and [Horror stories](#) from SpecialChild.com. This website features stories contributed by parents of children with a variety of disabilities. Updated regularly, parents can add their personal stories by e-mailing SuccessStory@specialchild.com.

Additional Resources on Multiple Disabilities

- [Tips from Specialkids.com](#) provide some sense of the various factors that must be considered by parents of children with complex needs. Each of the links give a list of suggestions that parents have generated to deal with these day-to-day events.
 - [Strategies](#) for meeting the educational needs of students with multiple severe/profound physical and cognitive disabilities. A team, consisting of a teacher, occupational therapist, physiotherapist, and speech-language pathologist provide support through a variety of services.
 - [Ashley's Mom, Inc.](#) In keeping with the spirit of the "mother of invention" this site was "born" out of necessity for finding creative ways to provide meaningful education for children with multiple disabilities.
 - ["Our Rays of Sunshine"](#) On the following pages you will find the stories of some of our children: For all of us our children are shining lights in our lives. Most of us are our children's prime advocates and voices. Many of the medical community still do not think our kids are "worth" caring for or saving. We have all worked hard to prove them wrong, and to find Doctors and medical staff who value our children. Now, through this web site we are able to publicly acknowledge their accomplishments.
- [Our-Kids](#) list consist of people representing children of varying diagnosis; everything from indefinite developmental delays and sensory integration problems, to cerebral palsy, to rare genetic disorders. Over 35 countries are represented on the list now. Ashley formed our-Kids in January 1993, on behalf of her son Austin who has Angelman Syndrome.
- [Personal Stories](#) This site features personal stories from individuals and parents with Chronic, Infantile, Neurologic, Cutaneous and Articular syndrome or Neonatal Onset Multi-Inflammatory Disease.
 - [PKU Personal Stories](#) A list of stories offered by parents of children with phenylketonuria (an inherited metabolic disease that results in mental retardation and other neurological problems when treatment is not started within the first few weeks of life). The list offers a variety of tips and personal experiences in raising their children and addressing their specific needs.
 - [RJ's Website](#) This is the home page for RJ and his family. RJ, tragically was recently diagnosed with a terminal illness called Tay-Sachs Disease. Tay-Sachs is a rare genetic disorder that results in a deterioration of the central nervous system.

Additional Resources on Deafblindness

- [Overview on Deaf-Blindness](#) from the National Information Clearinghouse On Children Who Are Deaf-Blind is a federally funded information and referral service that identifies, coordinates, and disseminates (at no cost) information related to children and youth who are deaf-blind
- [A-Z to Deafblindness](#) A-Z to Deafblindness is here to try and help Deafblind people on the net, to make people more aware about Deafblindness, and to let people know about some of the equipment that people with deafblindness use.
- [Helen Keller National for Deaf-Blind Youths & Adults](#)
- [Nat'l Info Clearinghouse on Children Who Are Deaf-Blind](#) Free publications from a government referral service that disseminates information related to deaf-blind children.
- [20/20 Interview of Bob and Michelle Smithdas](#) "October 25, 1998 When asked what her most memorable interview ever was, Barbara Walters responded, 'It is not a president or a king or a movie star. It is a man I interviewed more than 25 years ago. He was a teacher and a poet, and the most inspirational person I have ever met. His name is Robert Smithdas.' Now, more than 30 years later, Walters revisits Smithdas, who is now married to a woman who, like him, is deaf and blind. She reports how they manage to live independently; cooking by touch, using teletype-style phones and computers, wearing pagers that vibrate to signal the ringing of the telephone or the doorbell."

Sensory disability

There are many links on this page. This reflects the fact that you are dealing with two very different disabilities. There are also a large number of interesting and informative links related to the strong identity of the “deaf community” and the alternative modes of communication used by these two populations. Do not be overwhelmed, enjoy the materials and collect the information you need for our notebook entries.

Hearing Impairment

1. General Information about [Deafness And Hearing Loss](#) from NICHCY.
2. [National Association of the Deaf \(NAD\)](#) established in 1880, is the oldest and largest constituency organization safeguarding the accessibility and civil rights of 28 million deaf and hard of hearing Americans in education, employment, health care, and telecommunications. The mission of the National Association of the Deaf is to promote, protect, and preserve the rights and quality of life of deaf and hard of hearing individuals in the United States of America.
3. [Hearing Impairment](#) from TeensHealth! TeensHealth was created for teens looking for honest, accurate information and advice about health, relationships, and growing up. Created by The Nemours Foundation's for Children's Health Media, TeensHealth provide teens and families with accurate, up-to-date, and jargon-free health information they can use.
4. The discussion of [Deaf Culture and Community](#) at the National Association of the Deaf web site challenges to think about some of our assumptions.
5. [Perspective in Education and Deafness](#) - A Personal Reflection by Benna Timperlake
Benna Timperlake was president of the American Society for Deaf Children from 1994-1996. A resident of Corpus Christi, Texas, she is the mother of three children, including 11-year-old Genelle who is deaf. She offers her reflections on working with the deaf, as well as assisting her 11-year-old daughter.
<http://clerc.gallaudet.edu/products/perspectives/mar-apr97/forever.html>

Visual Impairment

1. General Information about [Visual Impairments](#) from NICHCY.
2. Founded in 1940, the [National Federation of the Blind](#) (NFB) is the nation's largest and most influential membership organization of blind persons. With fifty thousand members, the NFB has affiliates in all fifty states plus Washington D.C. and Puerto Rico, and over seven hundred local chapters. As a consumer and advocacy organization, the NFB is considered the leading force in the blindness field today. The purpose of the National Federation of the Blind is two-fold—to help blind persons achieve self-confidence and self-respect and to act as a vehicle for collective self-expression by the blind.
3. Kenneth Jernigan is a long time activist in the area of blindness and visual impairments. He discusses an appropriate [definition of blindness](#).
4. [Visual Impairment](#) from TeensHealth! TeensHealth was created for teens looking for honest, accurate information and advice about health, relationships, and growing up. Created by The Nemours Foundation's for Children's Health Media, TeensHealth provide teens and families with accurate, up-to-date, and jargon-free health information they can use.
5. [Personal story](#) of Sarah Blake reflecting on her experience growing up as a blind person.
<http://www.growingstrong.org/blindness>

Additional Information on Hearing Impairment



- Go to [Silent Thunder](#) to learn some American Sign Language signs & fingerspelling.
 - [History Through Deaf Eyes](#) This exhibition places the social history of deaf Americans within the context of better-known aspects of American history. The exhibition's goal is to make the deaf experience accessible to hearing Americans. <http://depts.gallaudet.edu/deafeyes/>
- T** [SERI Hearing Impairment Resources](#) SERI Hearing Impairment Resources: Deaf Education Website <http://www.seriweb.com/hearing.htm>

Additional Information on Visual Impairment

- [American Printing House for the Blind](#) Founded in 1858, The American Printing House for the Blind, Inc. (APH) is the world's largest company devoted solely to creating products for people who are visually impaired <http://www.aph.org/>
- [National Library Service for the Blind & Physically Handicapped \(Library of Congress\)](#) National Library Service for the Blind and Physically Handicapped administers a free library program of Braille and recorded materials circulated to eligible borrowers. <http://lcweb.loc.gov/nls>
- [The Blind Readers' Page](#) This site is a guide to sources of information in alternative formats (Braille, recorded cassettes, large print, e-texts, etc. <http://www.execpc.com/~wgraczyk/blndrdrs.html>
- [A Blind Net - Intro Page](#) Blind People Need Equality, Not Random Acts Of Senseless Kindness. Click here to find out why. <http://www.blind.net>
- [Resources on Visual Impairment](#) What is Visual Impairment? Organizations for the Blind. General Resources for the Visually Impaired. Braille Resources., Etc.. <http://curry.edschool.virginia.edu/go/cise/ose/categories/vi.html>

Additional stories of people with deafness & hearing impairment and their families

- [Gripe Stories from the Deaf Community](#) On this website, candid issues that face members of the deaf community are addressed through a series of postings by individuals who are deaf. <http://members.tripod.com/~deafwatch/gdeaf.htm>
- [DeafWeb](#) features a number of short stories by Branden Huxtable. Branden walks readers through a number of personal experiences that challenged his transition into a hearing society. Examples of some of these personal perspectives are included below. <http://www.deafweb.org/soapbox.htm>

Additional stories of people with blindness & visual impairment and their families

- [Charlie's Place](#) (<http://members.aol.com/CharlieF74/index.html>) The personal website for Charlie, a 44-year-old man who lists as his hobbies: long walks, woodworking, computers, various crafts, and gardening. His personal webpage features poems, links to various visual impairment resources, and some jokes.
- [Blindness - Personal Stories](#) (<http://www.blindness.org/html/coping/wfamily.html>) The Foundation Fighting Blindness has collected a series of short stories offered by persons with significant vision impairments. This assortment of stories offers candid personal reflections on how they have addressed their vision impairments.
- [Pshon's Page](#) (<http://www.geocities.com/Heartland/Bluffs/1646/blindness.htm>) This page features some stories and funny anecdotes by Shon, an individual with a visual impairment.

- **Adjustment to Blindness and Visual Impairments - Short Stories by Robert Leslie Newman** (<http://falcon.creighton.edu/vip/stories.htm>) We have been living with blindness for as long as mankind has been able to see. One of the best ways to tell these stories is through a fictionalized account. This page presents stories written by Robert Leslie Newman and others.

Spina Bifida

Spina Bifida is a physical disability that occurs very early in a newly conceived child's development. It takes several forms and has some other related conditions that must be considered. The first four sites listed will give you a great deal of information about this condition. As you prepare your notebook entries, if you want more information, the additional links give you plenty of good resources.

1. [NICHCY - Spina Bifida fact sheet](http://www.nichey.org/pubs/factshe/fs12txt.htm) As with all of the fact sheets, this one provides a very concise summary of the basic facts about this condition. <http://www.nichey.org/pubs/factshe/fs12txt.htm>
2. [The website of SBH of Queensland](http://www.spinabifida.org/Spina%20Bifida.htm), Australia provides an easy to understand, well illustrated guide to Spina Bifida and related conditions at <http://www.spinabifida.org/Spina%20Bifida.htm> The 14 pages on this site provide a very complete overview of this condition. Reviewing it will build on the basic concepts introduced in the NICHCY website.
3. [Spina Bifida Association of America](http://www.sbaa.org/) This is the home page of the Spina Bifida Association of America, the leading national organization concerned primarily with this condition. <http://www.sbaa.org/>
4. [Living With Spina Bifida](http://www.livingwithsb.com/ourfamily.html) a family's story. This mother summarizes the events around her daughter's birth and then provides a chronology of events over her 18 months of life. All of the links on the homepage present interesting and informative material. <http://www.livingwithsb.com/ourfamily.html>

Additional Information

- [Spina Bifida Association of America - Facts About Spina Bifida](http://www.sbaa.org/html/sbaa_facts.html) The national organization's effort to provide its members and the public with accurate and up to date information. http://www.sbaa.org/html/sbaa_facts.html
- [Association for Spina Bifida and Hydrocephalus - Information Pages](http://www.asbah.org) This is the British association for people with spina bifida and their families. It also has a well illustrated information section...<http://www.asbah.org>
- [Family Village: Spina Bifida Site](http://www.familyvillage.wisc.edu/lib_spin.htm) Like all of the links to this group, this one provides medical information, a list of contacts, mailing lists and a selection of related links at http://www.familyvillage.wisc.edu/lib_spin.htm.
- [Children with Spina Bifida: A Resource Page for Parents & Professionals](http://www.waisman.wisc.edu/~rowley/sb-kids/index.htmlx)
A resource page for parents of children with spina bifida and health professionals.
<http://www.waisman.wisc.edu/~rowley/sb-kids/index.htmlx>

The stories of other people with spina bifida and their families

- [Susete's Home Page](#) Susete Callahan's story about the birth of her son with Spina Bifida.
- [Meet Julia](http://www.juliasjourney.com). A site created by her mother who says, "She was born with Hydrocephalus and Spina Bifida. To us, she's perfect and a miracle. I created "Julia's Journey" to share our story about having a child born with a serious birth defect called Spina Bifida and a condition called Hydrocephalus". <http://www.juliasjourney.com> This site also has [Links to Other SB Families](#). Some very interesting stories, but about half of the links are no longer active.

Syndrome Disorders

According to *Merriam Webster's Medical Dictionary*, a syndrome is “a group of signs and symptoms that occur together and characterize a particular abnormality.” This topic is intended to put you in touch with a wide variety of low incidence conditions which can affect human growth and development. Our first link is to an organization called the National Organization for Rare Disorders. It says that there are over 6,000 such conditions and that they affect about 25,000,000 people in the USA alone. You or a member of your family may have one of these conditions. Obvious most of these conditions do not lead to someone needing special education, but many can.

As you work with students with moderate and severe disabilities, you are certainly interacting with individuals who have some of these conditions. At one time not so long ago, the records of people with these conditions would said, “there is no identifiable cause for this condition.” The advances in genetic research over the last few years have now enabled us to trace the basic genetic and chromosomal differences for many conditions. So some understanding of genetics is important as we discuss syndrome disorders. Nevertheless, look at the definition again. It does not say a syndrome has to be a genetic condition. A syndrome disorder can have other causes; the best example of this is Fetal Alcohol Syndrome. This group of distinctive characteristics is caused by a mother’s consumption of alcohol during pregnancy.

There is a lot here. We do not expect you to become a master of genetics and thousands of conditions! Prepare your notebook with a focus on the large issues of the challenge of providing support to people with very rare and distinctive conditions. Why is this important? Why do teachers and others need some of this information? The first four links will give you plenty of information for completing that task. Then switch focus and look into the Disorder Zone (#4). Choose five of the numerous syndrome conditions listed and read about them. Finally, prepare a half a page summary of what you learned. Remember — you *cannot* do it on some of the conditions like Down syndrome or Asperger syndrome that are discussed on other pages. In making your choice, you may want to first select conditions that one of your peers has. The added links and the information in the disorder zone will make this fairly manageable.

1. [National Organization for Rare Disorders](#) (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. According to NORD “A rare disorder affects fewer than 200,000 people in the United States. There are more than 6,000 rare disorders that, taken together, affect approximately 25 million Americans.”
2. [Genetics and Mental Retardation](#) is a four-page newsletter published by the Arc's Human Genome Education Project. It highlights the ethical, legal and social issues surrounding genetic research and mental retardation. It provides a background on genetic and how it causes many forms for disability. Additional material pursuing this question in greater depend can be found at the [Human Genome Education Project Web page](#).
3. [Diagnosis Search](#) at Specialkids.com provides a forum for parents who are anxiously searching for a diagnosis of their child’s condition. A photograph and description of the child’s characteristics are posted. Be sure to follow the link at the bottom of the first page to see the remaining 19 children who are listed. Click on the picture on the second page to see the information about the child. Note the three children whose diagnoses have been found.
4. [The Disorder Zone](#) provides information on 40 conditions; of these, 29 are described as syndrome disorders. The site authors note that, “This site has been created for educational purposes only and is not intended to serve as medical advice. The information provided in The Disorder Zone should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. If your child has any health concerns, please consult your health care provider.”

Links to disorder specific organizations

- [Angelman Syndrome Foundation \(ASF\)](#) Foundation established to help answer questions and provide a network of information, education and support resources to Angelman Syndrome families and friends.
- [CHARGE Syndrome Association](#) Provides information about CHARGE syndrome, related disorders, therapies and outcome.
- [Fetal Alcohol Syndrome Family Resource Institute](#)
The mission of the Institute is to identify, understand and care for individuals disabled by prenatal alcohol exposure and their families, and to prevent future generations from having to live with this disability.
- [National Organization on Fetal Alcohol Syndrome \(NOFAS\)](#) is a nonprofit organization founded in 1990 dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected. NOFAS, the only national organization focusing solely on FAS, takes a multicultural approach to prevention and healing.

- [**FRAXA Research Foundation**](#) was founded in 1994 by three parents of children with **fragile X syndrome**, Katie Clapp, Michael Tranfaglia, MD, and Kathy May, to support scientific research aimed at finding a treatment and a cure for fragile X syndrome. Fragile X research is drastically underfunded, considering its high prevalence, prospects for a cure, and the promise that this research holds for advancing understanding of other disorders like autism, Alzheimer's disease, and X-linked mental retardation.
 - [**The American Association for Klinefelter Syndrome Information and Support**](#) (AAKSIS) was incorporated on December 14, 1999. AAKSIS (pronounced "access") is a national volunteer organization with the mission of education, support, research and understanding of XXY and its variants, collectively known as Klinefelter Syndrome.
 - [**Prader-Willi Syndrome Association \(USA\)**](#) (PWSA(USA)) The Prader-Willi Syndrome Association was organized in the United States in 1975 to serve as an international vehicle of communication about Prader-Willi syndrome .
 - [**Tourette Syndrome Association, Inc.**](#), (TSA) Founded in 1972 in Bayside, New York, this is the only national voluntary non-profit membership organization in this field. Its mission is to identify the cause of, find the cure for, and control the effects of this disorder.
 - [**Support Org. for Trisomy 18, 13 and Related Disorders**](#), (SOFT) Organization offers support and education for parents of children with a chromosome disorder, particularly trisomy 13 and 18.
- [**Williams Syndrome Association**](#) (WSA) was formed in 1982 by, and for families of individuals with Williams syndrome. It is the only group in the nation devoted exclusively to improving the lives of individuals with Williams syndrome and their families. The association supports research into all facets of the syndrome, and the development of educational materials regarding Williams syndrome.