

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Intellectual or Cognitive Disability

Job Accommodation Network
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Morgantown, WV 26506-6080
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(877)781-9403 (TTY)
jan@askjan.org
AskJAN.org



Funded by a contract with the Office of Disability
Employment Policy, U.S. Department of Labor

Preface

The Job Accommodation Network (JAN) is funded by a grant from the Office of Disability Employment Policy, U.S. Department of Labor. JAN makes documents available with the understanding that the information be used solely for educational purposes. The information is not intended to be legal or medical advice. If legal or medical advice is needed, appropriate legal or medical services should be contacted.

JAN does not endorse or recommend any products or services mentioned in this publication. Although every effort is made to update resources, JAN encourages contacting product manufacturers/vendors and service providers directly to ensure that they meet the intended purposes. This guarantees that the most up-to-date information is obtained.

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Updated 02/27/2024.

JAN'S Accommodation and Compliance Series

Introduction

JAN's Accommodation and Compliance Series is designed to help employers determine effective accommodations and comply with Title I of the Americans with Disabilities Act (ADA). Each publication in the series addresses a specific medical condition and provides information about the condition, ADA information, accommodation ideas, and resources for additional information.

The Accommodation and Compliance Series is a starting point in the accommodation process and may not address every situation. Accommodations should be made on a case by case basis, considering each employee's individual limitations and accommodation needs. Employers are encouraged to contact JAN to discuss specific situations in more detail.

For information on assistive technology and other accommodation ideas, visit JAN's Searchable Online Accommodation Resource (SOAR) at <https://AskJAN.org/soar>.

Information about Intellectual Disability

According to the [American Association on Intellectual and Developmental Disabilities](#), an intellectual disability is a disability that involves significant limitations both in intellectual functioning and in adaptive behavior. Adaptive behaviors include many everyday social and practical skills such as interpersonal and communication skills, social problem solving and responsibility, the use of time and money, as well as daily personal care and safety. Limitations in individuals often coexist with strengths, and will vary from individual to individual.

This disability originates before the age of 18 and encompasses a wide range of conditions, types, and levels. Intellectual disability is caused by factors that can be physical, genetic, and/or social. According to the [President's Committee for People with Intellectual Disabilities](#), an estimated seven to eight million Americans of all ages experience intellectual disability. Intellectual disabilities affect about one in ten families in the United States.

- JAN's [Accommodation Solutions: Executive Functioning Deficits](#) is a publication detailing accommodations for individuals with limitations related to executive functioning. These ideas may be helpful in determining accommodations.
- JAN's [Effective Accommodation Practices \(EAP\) Series: Communication Tips for Working with Individuals with Intellectual Disabilities](#) is a publication discussing strategies for communicating with individuals who process information more slowly.

Additional Helpful Terminology

Developmental disabilities that may also include an intellectual disability are briefly described below. Intellectual disabilities can also be caused by a head injury, stroke or illness. For some no cause is found. Intellectual disabilities will vary in degree and effect from person to person, just as individual capabilities vary considerably among people who do not have an intellectual disability. People should not make generalizations about the needs of persons with intellectual disabilities. In some instances an intellectual disability will not be obvious from a person's appearance, nor will it be accompanied by a physical disability. Persons with intellectual disabilities successfully perform a wide range of jobs, and can be dependable workers. (EEOC, 2011)

Autism: Individuals with disabilities on the autism spectrum may have complex developmental disabilities that typically appear during the first three years of life. These disabilities are the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with disabilities on the autism spectrum typically show difficulties in verbal and non-verbal communication, social interactions, and play or leisure activities.

Cerebral Palsy is a condition, sometimes thought of as a group of disorders, that can involve brain and nervous system functions such as movement, learning, hearing, seeing, and thinking. Cerebral palsy is caused by injuries or abnormalities of the brain. Most of these problems occur as the baby grows in the womb, but they can happen at any time during the first two years of life, while the baby's brain is still developing.

Down Syndrome is a genetic disorder that causes lifelong intellectual disabilities, developmental delays and other complications. Down syndrome varies in severity, so developmental problems range from moderate to serious. Down syndrome is the most common genetic cause of severe intellectual disabilities in children. Individuals with Down syndrome have a higher incidence of heart defects, leukemia, sleep apnea, and dementia later in life.

Fetal Alcohol Syndrome is a condition that results from prenatal alcohol exposure. It is a cluster of mental and physical birth defects that include intellectual disabilities, growth deficits, central nervous system dysfunction, craniofacial abnormalities and behavioral instabilities. Fetal Alcohol Effect is a less severe set of the same symptoms. It is the only form of intellectual disability that can be totally prevented and eradicated.

Fragile X Syndrome is a hereditary condition that can cause learning problems ranging from subtle learning disabilities and a normal IQ, to severe intellectual disabilities and autism. Individuals with Fragile X Syndrome may also have physical and behavioral disorders, and speech and language delays.

Prader-Willi Syndrome (PWS) is the most common known genetic cause of life-threatening obesity in children. PWS typically causes low muscle tone, short stature if not treated with growth hormone, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive

eating and life-threatening obesity. PWS is also characterized by motor development delays along with some behavior problems and unique medical issues. Intellectual deficits can be present to varying degrees, but even higher functioning individuals will have learning difficulties.

Intellectual Disability and the Americans with Disabilities Act

The ADA does not contain a definitive list of medical conditions that constitute disabilities. Instead, the ADA defines a person with a disability as someone who (1) has a physical or mental impairment that substantially limits one or more "major life activities," (2) has a record of such an impairment, or (3) is regarded as having such an impairment. For more information about how to determine whether a person has a disability under the ADA, see [How to Determine Whether a Person Has a Disability under the Americans with Disabilities Act Amendments Act \(ADAAA\)](#).

Accommodating Employees with Intellectual Disability

People with intellectual or cognitive disabilities may develop some of the limitations discussed below, but seldom develop all of them. Also, the degree of limitation will vary among individuals. Be aware that not all people with intellectual or cognitive disabilities will need accommodations to perform their jobs and many others may only need a few accommodations. The following is only a sample of the possibilities available. Numerous other accommodation solutions may exist.

Questions to Consider:

1. What limitations is the employee experiencing?
2. How do these limitations affect the employee and the employee's job performance?
3. What specific job tasks are problematic as a result of these limitations?
4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
5. Once accommodations are in place, would it be useful to meet with the employee to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
6. Do supervisory personnel and employees need training?

Accommodation Ideas:

Limitations

Executive Functioning Deficits

- Apps for Concentration
- Apps for Memory
- Calendars and Planners
- Checklists
- Color Coded System
- Cubicle Doors, Shields, and Shades
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Extra Time
- Flexible Schedule
- Form Generating Software
- Full Spectrum or Natural Lighting Products
- Job Coaches
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Noise Canceling Earbuds
- Noise Canceling Headsets
- On-site Mentoring
- Recorded Directives, Messages, Materials
- Reminders
- Sound Absorption and Sound Proof Panels
- Speech Recognition Software
- Sun Boxes and Lights
- Sun Simulating Desk Lamps
- Timers and Watches
- Written Instructions

Managing Time

- Applications (apps)
- Apps for Organization/ Time Management
- Calendars and Planners
- Checklists
- Color Coded System
- Electronic Organizers
- Marginal Functions
- PDAs, Notetakers, and Laptops
- Personal On-Site Paging Devices
- Reminders
- Task Separation
- Timers and Watches
- Written Instructions

Mathematics

- Construction Calculators
- Counting/Measuring Aids
- Fractional, Decimal, Statistical, or Scientific Calculators
- Large Display Calculators or Adding Machines
- Large Display Thermometers
- Mathematics Software
- Talking Calculators
- Talking Scales
- Talking Tape Measures
- Talking Thermometers
- Talking Watches

Memory Loss

- Additional Training Time / Training Refreshers
- Apps for Memory
- Calendars and Planners

- Electronic Organizers
- Job Coaches
- Professional Organizers
- Recorded Directives, Messages, Materials
- Reminders
- Social Skill Builders
- Support Person
- Verbal Cues
- Visual Schedulers
- Written Instructions

Organizing/Planning/Prioritizing

- Applications (apps)
- Apps for Organization/ Time Management
- Calendars and Planners
- Color-coded Manuals, Outlines, and Maps
- Electronic Organizers
- Ergonomic Equipment
- Job Coaches
- Job Restructuring
- On-site Mentoring
- Organization Software
- Personal On-Site Paging Devices
- Professional Organizers
- Reminders
- Supervisory Methods
- Task Identification
- Task Separation
- Timers and Watches
- Visual Schedulers
- Written Instructions

Reading

- Color Contrast Overlays
- Color-coded Manuals, Outlines, and Maps
- Literacy Skills Development
- Modified Written Materials
- On-Screen "Ruler" / Strip
- Optical Character Recognition (OCR) Systems - Scan
- Portable or Handheld Readers
- Qualified Reader
- Reading / Highlighting Products
- Reading Pen
- Screen Magnification and Screen Reading Combined
- Screen Magnification Software
- Screen Reading Software and Training
- Text Reader
- Word Processing Software

Writing/Spelling

- Electronic Dictionaries
- Form Generating Software
- Line Guides
- Literacy Skills Development
- PDAs, Notetakers, and Laptops
- Proofreading/ Copyediting Assistance
- Reference Books
- Screen Reading Software and Training
- Speech Recognition Software
- Verbal Responses
- Word Prediction/Completion and Macro Software
- Word Processing Software
- Writing Aids
- Writing/Editing Software

- Written Forms and Prompts

Work-Related Functions

Use Cognitive Function

- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Color Coded System
- Counting/Measuring Aids
- Electronic Dictionaries
- Electronic Organizers
- Extra Time
- Fractional, Decimal, Statistical, or Scientific Calculators
- Job Coaches
- Line Guides
- Marginal Functions
- Modified Break Schedule
- On-site Mentoring
- Personal On-Site Paging Devices
- Professional Organizers
- Reassignment
- Reminders
- Service Animal
- Social Skill Builders
- Support Person
- Training Modifications
- Uninterrupted Work Time

Work Site Access

- Accessible Toilets and Toilet Seats
- Accessories for Scooters
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings

- All-Terrain Scooters
- Anti-fatigue Matting
- Automatic Door Openers
- Boat Access
- Braille and/or ADA Signage
- Door Knob Grips and Handles
- Examination and Procedures Chair
- Flexible Schedule
- Head Support for Wheelchairs
- High Visibility Floor Tape and Paint
- Low Task Chair
- Portable Ramps
- Ramps
- Scooters
- Service Animal
- Smart Locks/Keyless Entry Locks
- Stair Assists
- Stair Tread/Textured Tape
- Support Animal
- Telework, Work from Home, Working Remotely
- Van Conversion
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Lifts
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Work Station Access

- Accessories for Scooters

- Adjustable and Ergonomic School Desks and Equipment
- Adjustable Desk Top Workstations for Office Settings
- Adjustable Workstations for Industrial Settings
- All-Terrain Scooters
- Anti-fatigue Matting
- Articulating Keyboard Trays
- Assist Lift Cushions
- Automatic Door Openers
- Chair Mats
- Chairs for Little People
- Chairs for People who are Tall
- Dual Monitors
- Elevating Lift and Office Chairs
- Ergonomic and Adjustable Office Chairs
- Ergonomic Equipment
- Examination and Procedures Chair
- Expanded Keyboards
- Forearm Support
- Forward Leaning Chairs
- Head Support for Wheelchairs
- Large-Rated Chairs
- Low Task Chair
- Monitor Mirrors
- Monitor Risers
- Mousing Surfaces
- Proper Sitting / Standing Techniques
- Stair Assists
- Stand-lean Stools
- Supine Workstations
- Van Conversion
- Wheelchair Accessible Scales

- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs
- Work Platforms
- Zero Gravity (reclining) Chairs

Situations and Solutions:

The following situations and solutions are real-life examples of accommodations that were made by JAN customers. Because accommodations are made on a case-by-case basis, these examples may not be effective for every workplace but give you an idea about the types of accommodations that are possible.

A production worker with an intellectual impairment and cerebral palsy had difficulty grasping a plastic bottle to accurately apply an adhesive label.

JAN suggested making a wooden jig, which secured the bottle, thus allowing the employee to use both hands when applying the label.

A gaming store clerk with Fragile-X did not know her ABCs and could not read movie titles.

She had difficulty stocking returned video games to the shelf. JAN suggested the employer make picture labels for the cases that matched shelf display boxes. This allowed the employee to match pictures, not words, when returning games to the shelf.

A grocery stocker with a cognitive impairment could not remember to wear all parts of his uniform.

JAN suggested taking a picture of the employee in full uniform and providing the picture to use as a reference when preparing for work.

A store clerk with an intellectual impairment had limited reading skills, making it difficult to return items to the shelf.

JAN suggested making picture labels for cases that matched shelf display boxes. This allowed the employee to match pictures, not words, when returning items to the shelf.

Products

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource at <https://AskJAN.org/soar> is designed to let users explore various accommodation options. Many product vendor lists are accessible through this system; however, JAN provides these lists and many more that are not available on the Web site upon request. Contact JAN directly if you have specific accommodation situations, are looking for products, need vendor information, or are seeking a referral.

Resources

Job Accommodation Network

West Virginia University
PO Box 6080
Morgantown, WV 26506-6080
Toll Free: (800) 526-7234
TTY: (304) 293-7186
Fax: (304) 293-5407
jan@askjan.org
<https://askjan.org>

The Job Accommodation Network (JAN) is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Office of Disability Employment Policy

200 Constitution Avenue,
NW, Room S-1303
Washington, DC 20210
Toll Free: (866) 633-7365
odep@dol.gov
<https://www.dol.gov/agencies/odep>

The Office of Disability Employment Policy (ODEP) is an agency within the U.S. Department of Labor. ODEP provides national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment.

Administration on Intellectual and Developmental Disabilities (AIDD)

One Massachusetts Avenue NW
Washington, DC 20001
Direct: (202) 401-4634
MJ.Karimie@acl.hhs.gov
<http://www.acl.gov/programs/aidd/Programs/PCPID/>

Acts in an advisory capacity to the President and the Secretary of Health and Human Services on matters relating to programs and services for persons with intellectual disabilities.

American Association on Intellectual and Developmental Disabilities

501 3rd Street, NW
Suite 200
Washington, DC 20001
Toll Free: (800) 424-3688
Direct: (202) 387-1968
Fax: (202) 387-2193
<http://www.aaid.org>

American Association on Intellectual and Developmental Disabilities (AAIDD) has been providing worldwide leadership in the field of intellectual and developmental disabilities. We're a powerful community of leaders with a strong voice and important mission.

American Occupational Therapy Association

6116 Executive Boulevard, Suite 200
North Bethesda, MD 20852-4929
Direct: (301) 652-6611
members@aota.org
<https://www.aota.org/>

The American Occupational Therapy Association (AOTA) is the national professional association established in 1917 to represent the interests and concerns of occupational therapy practitioners and students of occupational therapy and to improve the quality of occupational therapy services.

American Physical Therapy Association

<http://www.moveforwardpt.com/Default.aspx>

MoveForwardPT.com is the official consumer information website of the American Physical Therapy Association.

Association of People Supporting EmploymentFirst

416 Hungerford Dr.,
Suite 418
Rockville, MD 20850
Direct: (301) 279-0060
Fax: (301) 279-0075
membership@apse.org
<http://apse.org/>

Through advocacy and education, APSE advances employment and self-sufficiency for all people with disabilities

Autism Society

4340 East-West Hwy
Suite 350
Bethesda, MD 20814-3067
Toll Free: (800) 328-8476
TTY: (301) 657-0881
info@autism-society.org
<http://www.autismsociety.org/>

The Autism Society strives to empower individuals who experience Autism and their families to make informed decisions in the planning and delivery of individualized, evidence-based services and support.

Centers for Disease Control and Prevention

1600 Clifton Rd
Atlanta, GA 30333
Toll Free: (800) 232-4636
<https://www.cdc.gov/>

The Centers for Disease Control and Prevention are dedicated to protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

Down Syndrome International

Langdon Down Centre
2A Langdon Park
Teddington, Middlesex TW11 - 9PS
Direct: (440) 139-2357554
contact@ds-int.org
<https://ds-int.org>

Our mission is to improve quality of life for people with Down syndrome worldwide and promote their inherent right to be accepted and included as valued and equal members of society.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

31 Center Drive
Building 31, Room 2A32
Bethesda, MD 20892-2425
Toll Free: (800) 370-2943
Fax: (866) 760-5947
NICHDInformationResourceCenter@mail.nih.gov
<http://www.nichd.nih.gov/Pages/index.aspx>

The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

P.O. Box 3006
Rockville, MD 20847
Toll Free: (800) 370-2943
Fax: (866) 760-5947
NICHDInformationResourceCenter@mail.nih.gov
<http://www.nichd.nih.gov/Pages/index.aspx>

The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

Fetal Alcohol Spectrum Disorders: Center for Excellence

2101 Gaither Road
Suite 500
Rockville, MD 20850
Toll Free: (866) 786-7327
fasdcenter1@ngc.com
<http://www.fascenter.samhsa.gov/>

The mission of the FASD Center for Excellence is to facilitate the development and improvement of behavioral health prevention and treatment systems in the United States by providing national leadership and facilitating collaboration and information sharing in the field.

Foundation for Prader-Willi Research

FPWR
DEPT LA 23216
Pasadena, CA 91185-3216
Direct: (888) 322-5487
Fax: (888) 559-4105
info@fpwr.org
<https://www.fpwr.org/>

The mission of FPWR is to eliminate the challenges of Prader-Willi syndrome through the advancement of research. High-quality research will lead to more effective treatments and an eventual cure for this disorder. By working together, we intend to free our loved ones from the burdens of PWS, allowing them to lead full and independent lives.

Genetic and Rare Diseases Information Center (GARD)

P.O. Box 8126

Gaithersburg, MD 20898-8126

Toll Free: (888) 205-2311

Fax: (301) 251-4911

<https://rarediseases.info.nih.gov/>

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences (NCATS) and funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

Global Down Syndrome Foundation

3300 East First Avenue

Suite 390

Denver, CO 80206

Direct: (303) 321-6277

info@globaldownsyndrome.org

<http://www.globaldownsyndrome.org/>

Our goal is to significantly improve the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. We work to educate governments, educational organizations and society in order to affect legislative and social changes so that every person with Down syndrome has an equitable chance at a satisfying life.

The Global Down Syndrome Foundation created and organizes the Be Beautiful Be Yourself Fashion Show – the single-largest annual fundraiser benefiting people with Down syndrome. Global organizes and funds many programs, conferences and grants, including Dare to Play Football Camp with Ed McCaffrey, Denver Broncos Cheerleaders Dare to Cheer Camp, Junior Denver Broncos Cheerleaders Dare to Cheer Program, Be Beautiful Be Yourself Hollywood Ball and the Global Down Syndrome Foundation Educational Grants.

Jewish Association for Developmental Disabilities (J-ADD)

190 Moore Street
Suite 272
Hackensack, NJ 07601-7418
Direct: (201) 457-0058
Fax: (201) 457-0025
info1@j-add.org
<http://www.j-add.org/>

Through Residential, Vocational, and Respite services J-ADD has been on the front lines of improving the lives of those with intellectual and developmental disabilities.

Mayo Clinic

13400 E. Shea Blvd.
Scottsdale, AZ 85259
Direct: (480) 301-8000
<http://www.mayoclinic.org/>

The Mayo Clinic's mission to inspire hope and contribute to health and well-being by providing the best care to every patient through integrated clinical practice, education and research.

National Association for Down Syndrome

1460 Renaissance Drive
Suite #405
Park Ridge, IL 60068
Direct: (630) 325-9112
Fax: (847) 376-8908
info@nads.org
<http://www.nads.org/>

The National Association for Down Syndrome supports all persons with Down syndrome in achieving their full potential.

National Association of Councils on Developmental Disabilities

1825 K Street, NW,
Suite 600
Washington, DC 20006
Direct: (202) 506-5813
Fax: (202) 506-5846
info@nacdd.org
<http://www.nacdd.org/home/>

NACDD is the national association for the 56 State and Territorial Councils on Developmental Disabilities (DD Councils) which receive federal funding to support programs that promote self-determination, integration, and inclusion for all Americans with developmental disabilities.

National Center for Biotechnology Information

8600 Rockville Pike
Bethesda, MD 20894
pubmedcentral@ncbi.nlm.nih.gov
<https://www.ncbi.nlm.nih.gov/>

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

National Down Syndrome Congress

30 Mansell Court
Suite 108
Roswell, GA 30076
Toll Free: (800) 232-6372
Direct: (770) 604-9500
Fax: (770) 604-9898
info@ndsccenter.org
<http://www.ndsccenter.org/>

The mission of the National Down Syndrome Congress is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome. The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

National Down Syndrome Society

666 Broadway, 8th Floor
New York, NY 10012
Toll Free: (800) 221-4602
info@ndss.org
<http://www.ndss.org/>

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.
The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. - See more at:
<http://www.ndss.org/About-NDSS/Mission-Vision/#sthash.sZLWVpyR.dpuf>

National Fragile X Foundation

2100 M Street, NW
Suite 170, Box 302
Washington, DC 20037-1233
Toll Free: (800) 688-8765
Fax: (202) 747-6208
natlfx@fragilex.org
<https://fragilex.org/>

The National Fragile X Foundation unites the Fragile X community to enrich lives through educational and emotional support, promote public and professional awareness, and advance research toward improved treatments and a cure for Fragile X.

National Human Genome Research Institute

31 Center Drive, MSC 2152
9000 Rockville Pike
Bethesda, MD 20892-2152
Direct: (301) 402-0911
Fax: (301) 402-2218
<https://www.genome.gov/>

NHGRI's mission has expanded to encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease. To that end NHGRI supports the development of resources and technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal and social implications (ELSI) of genome research. NHGRI also supports the training of investigators and the dissemination of genome information to the public and to health professionals.

National Organization on Fetal Alcohol Syndrome

1200 Eton Court, NW
Third Floor
Washington, DC 20007
Toll Free: (800) 666-6327
Direct: (202) 785-4585
Fax: (202) 466-6456
information @nofas.org
<http://www.nofas.org/>

The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. Founded in 1990, NOFAS is the only international, non-profit organization committed solely to FASD primary prevention, advocacy and support.

National PKU Alliance

P.O. Box 501
Tomahawk, WI 54487
Direct: (715) 437-0477
Fax: (715) 453-7670
Christine.Brown@NPKUA.org
<http://www.npkua.org/>

The National PKU Alliance works to improve the lives of families and individuals associated with PKU through research, support, education and advocacy, while ultimately seeking a cure.

Pediatric Brain Foundation

2144 E. Republic Rd.
Building B, Suite 202
Springfield, MO 65804
Direct: (417) 887-4242
info@pediatricbrainfoundation.org
<http://www.pediatricbrainfoundation.org/>

Pediatric Brain Foundation's Mission is Three-fold:

- Expedite scientific research to find treatments and cures for the more than 14 million children living with some form of neurological disorder
- Provide families and health care professionals with up-to-date information and resources on the latest discoveries in pediatric neurology
- Educate the public and public officials on the critical importance of funding pediatric neurological research

Prader-Willi Syndrome Association (USA)

8588 Potter Park Drive,
Suite 500
Sarasota, FL 34238
Toll Free: (800) 926-4797
Direct: (941) 312-0400
Fax: (941) 312-0142
<http://pwsausa.org/>

Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome. Prader-Willi Syndrome Association (USA) will be a self-sustaining, internationally recognized leader, empowering those affected with Prader-Willi syndrome to enjoy a productive life in an informed and accepting community.

The Arc

1825 K Street, NW,
Suite 1200
Washington, DC 20006
Toll Free: (800) 433-5255
Direct: (202) 534-3700
Fax: (202) 534-3731
info@thearc.org
<http://thearc.org>

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. We encompass all ages and more than 100 different diagnoses including autism, Down syndrome, Fragile X syndrome, and various other developmental disabilities.

The PKU Foundation

1230 East Ledbetter Drive
Dallas, TX 75216
Direct: (214) 446-4003
dpearson@pkufoundation.com
<https://www.pkufoundation.com>

It is our desire for this Foundation to serve as a central, national fundraising organization with the express purpose of helping those effected with Phenylketonuria (PKU). This rare genetic disorder does not yet have a campaign platform from which to raise funds and collect donations on a national level, and that is an important gap The PKU Foundation would like to fulfill.

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