

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Marfan Syndrome

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ODEP

Office of Disability
Employment Policy

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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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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 Marfan Syndrome

Marfan syndrome is a genetic disorder of the connective tissue that can affect the skeleton, lungs, eyes, heart, and blood vessels. The condition affects both men and women of any race or ethnic group. It is estimated that at least 200,000 people in the United States have Marfan syndrome or a related connective tissue disorder.

Characteristics of the disorder vary greatly, but the most common problems associated with Marfan syndrome include heart problems, scoliosis, and near-sightedness. There is no cure for the disorder yet, but careful medical management can greatly improve the prognosis and lengthen the life span.

Marfan Syndrome 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 Marfan Syndrome

People with Marfan syndrome 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 Marfan syndrome 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

Decreased Stamina/Fatigue

- Accessories for Scooters
- Aide/Assistant/Attendant
- All-Terrain Scooters
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic and Pneumatic Tools
- Ergonomic Assessments
- Ergonomic Equipment
- Examination and Procedures Chair
- Flexible Schedule

- Head Support for Wheelchairs
- Job Restructuring
- Low Task Chair
- Mechanic's Seats and Creepers
- Multi-Purpose Carts
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Lifting

- Accessible Baby Changing Stations
- Adjustable Exam Tables
- Adjustable Massage Tables
- Adult Changing Tables
- Aerial Lifts
- Animal Lift Tables
- Automated Filing Systems
- Ball Transfer Tables
- Bath Chairs
- Battery Powered Lift Tables
- Cake Decorating and Baking Equipment
- Carts
- Compact Material Handling
- Compact Mobile Cranes

- Drum Handling
- Drywall and Wallboard Lifts
- Electronic Organizers
- Engine Lifts and Lift Plates
- Ergonomic Assessments
- Ergonomic Equipment
- Evacuation Devices
- Folding Steps
- Hair Scissors
- Hands Free Resuscitation Devices
- Height Adjustable Table Legs
- Independent Living Aids
- Job Restructuring
- Large-Rated Small Step Ladders
- Large-Rated Wheelchair Lifts
- Lift Gates
- Lift Tables
- Lifters and Carriers for Mobility Aids
- Lifting Aids
- Light Switch Extension Handles
- Lightweight Lead Aprons
- Low Task Chair
- Manhole Cover Lifts
- Multi-Purpose Carts
- Patient Lifts (General)
- Periodic Rest Breaks
- Pickups, Semis, and Heavy Equipment
- Pipettes
- Pool Lifts
- Power Lift IV Stands
- Powered Bath Lifts

- Professional Organizers
- Proper Lifting Techniques
- Rolling Safety Ladders
- Spring-Loaded Carts
- Stainless Steel Carts and Worktables
- Stair Assists
- Stairclimbing Handtrucks
- Talking Bar Code Scanner/Reader
- Test Tube Holders
- Tire Handling
- Toileting Aids
- Tool Balancers
- Transfer Aids
- Transfer Sheets
- Truck Mounted Cranes
- Vacuum Lifts
- Vacuum Pickup Tools
- Vehicle Lifts and Manipulators
- Walk-up Changing Tables
- Wheelchair Lifts
- Winches and Chain Hoists
- Work Platforms

Stress Intolerance

- Apps for Anxiety and Stress
- Behavior Modification Techniques
- Counseling/Therapy
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Restructuring
- Marginal Functions

- Modified Break Schedule
- Supervisory Methods
- Support Animal
- Support Person

Work-Related Functions

Parking

- Accessible Parking Space
- Flexible Schedule
- Telework, Work from Home, Working Remotely
- Wheelchairs

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 customer service rep with Marfan syndrome which resulted in heart issues.

The employee needed to attend periodic medical appointments, but the appointments were scheduled during their shift at work. The employee requested leave and a flexible schedule as reasonable accommodations, which the employer approved on a temporary basis.

A paralegal with Marfan syndrome was experiencing fluctuating vision, therefore she was having trouble viewing her computer screen.

The employer noticed her having a hard time and purchased screen reading software which allowed her to continue performing her computer tasks.

A production worker in a manufacturing plant experienced fatigue which stemmed from Marfan syndrome.

The employer noticed her having a hard time and purchased screen reading software which allowed her to continue performing her computer tasks.

An human resources specialist for a department store was recently required to add a weekend shift to her work schedule once a month.

This caused significant stress which caused an exacerbation to her Marfan syndrome. After making a request for a flexible schedule along with medical documentation, the employer approved removing the weekend shift as an accommodation. This enabled the employee to work her regular schedule without worsening her symptoms.

A warehouse stock clerk with Marfan syndrome had lifting restrictions.

After realizing he was having a hard time performing his job tasks, he told his employer his concerns. The employer purchased a compact lifting device to enable the employee to continue lifting boxes and work within his medical restrictions.

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.

DNA Learning Center: Cold Spring Harbor Laboratory

Direct: (516) 367-5170
Fax: (516) 367-5182
<http://www.ygyh.org/index.htm>

Cold Spring Harbor Laboratory (CSHL) is a private, not-for-profit research and education institution at the forefront of molecular biology and genetics.

DNA Learning Centers's educate the public about genetics through the nation's first science centers dedicated to this purpose.

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.

Heart and Stroke Foundation of Canada

K1P 5V9

Ottawa

Direct: (613) 569-4361

Fax: (613) 569-3278

<http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.2796497/k.BF8B/Home.htm>

The mission of the Heart and Stroke Foundation of Canada is to further the study, prevention, and reduction of disability and death from heart disease and stroke through research, education, and the promotion of healthy lifestyles.

March of Dimes Foundation

1275 Mamaroneck Avenue

White Plains , NY 10605

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

The mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth and infant mortality.

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.

MedlinePlus

8600 Rockville Pike
Bethesda, MD 20894
custserv@nlm.nih.gov
<https://medlineplus.gov>

MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, the world's largest medical library, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free.

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 Heart, Lung, and Blood Institute

P.O. Box 30105

Attention: Website

Bethesda, MD 20824-0105

Direct: (301) 592-8573

Fax: (240) 629-3246

nhlbiinfo@nhlbi.nih.gov

<http://www.nhlbi.nih.gov/>

The National Heart, Lung, and Blood Institute (NHLBI) provides leadership for a national program in diseases of the heart, blood vessels, lung, and blood.

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 for Rare Disorders

55 Kenosia Avenue

Danbury, CT 06813-1968

Toll Free: (800) 999-6673

Direct: (203) 744-0100

Fax: (203) 263-9938

<http://www.rarediseases.org>

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.

The Marfan Foundation

22 Manhasset Avenue
Port Washington, NY 11050

Toll Free: (800) 862-7326

Direct: (516) 883-8712

Fax: (516) 883-8040

staff@marfan.org

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

Provides accurate and timely information about Marfan Syndrome to patients, family, members and physicians; to serve as a resource for medical information and patient support; and to support and foster research.

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