



# HELPING FORWARD

Employment Rights & Job Search Resources  
For People With Bleeding Disorders

Whether you have a bleeding disorder yourself or you are a caregiver to someone with a bleeding disorder, it is often a juggling act to live with a chronic condition and maintain your livelihood. This toolkit includes resources related to employment issues including insights from bleeding disorder community members, legislation to protect your rights, job search tools, interview tips, self-advocacy resources, and more.

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## COMMUNITY INSIGHTS

### HFA LEARNING CENTRAL

Employment Rights and Self-Advocacy Course

[www.hfalearning.org](http://www.hfalearning.org) (visit the Planning Office)

Engage in four self-paced, interactive lessons about employment rights created specifically for the bleeding disorders community. Learn practical information about the Americans with Disabilities Act and Family and Medical Leave Act and hear directly from 18 community members about their experiences and tips for self-advocacy in the workplace. Access the course in HFA Learning Central: sign in, visit the Planning Office, then click on Employment Rights.

### HFA WEBINARS

HFA Young Adults Hangout: Transitioning To Adulthood: Voices From The Community

<https://www.youtube.com/watch?v=ZcQuqCFQil8>

This recorded hangout featured young adults sharing their experiences of navigating school and the workplace with a bleeding disorder. An attorney from PSI's A.C.C.E.S.S Program joined to explain the rights of an employee with a bleeding disorder. (10/22/2014) Also see the [Accompanying HFA Dateline Federation article.](#)

HFA Families Webinar: Hi Ho, Hi Ho, It's Off To Work I (Don't) Go

<https://www.youtube.com/watch?v=ulzjiWhB2GE>

During this HFA Families Webinar, speakers from the U.S. Equal Employment Opportunity Commission and Department of Labor explained what the Family Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA) laws are, and how a parent can be eligible to use these benefits when you miss work due to your child's bleeding disorder. (3/16/2015)

HFA Young Adults Hangout – How to advocate for YOU

<https://www.youtube.com/watch?v=6-a4O0ScHCM>

Hear a presentation on insurance geared specifically for first time users, as well as first-hand perspectives from bleeding disorders community members who have successfully navigated health coverage and care. Panelists also spoke about advocacy as it relates to work, politics, and social media. (11/2016)

HFA Young Adults Hangout –Maintaining Boundaries: Employment in the Bleeding Disorders Community

<https://www.youtube.com/watch?v=EhzvmoueJ-Q>

Finding and securing employment can be exciting but often stressful for many young adults. For those living with bleeding disorders, the challenges are heightened. A position providing insurance benefits, an employer who upholds and respects your rights as a person living with a chronic disorder, and job flexibility, are not just 'nice to have,' but absolutely necessary. Many young adults find employment in the community a perfect fit for their skills and personal connection. However, juggling these roles can create ethical issues, such as maintaining boundaries, managing dual roles, determining conflicts of interest, upholding confidentiality, and appropriately using social media and other communication technology. This HFA hangout highlighted the experiences of young adults effectively managing their dual roles. (10/20/2015)

## HFA DEAR ADDY

Dear Addy is a regular advocacy feature from the Policy, Advocacy, and Government Relations Team at HFA that answers questions from the bleeding disorders community. The following links are Dear Addy answers related to employment issues.

COVID-19 And Employment Benefits, Insurance, And More - Panicked and Confused

[www.hemophiliafed.org/news-stories/2020/03/dear-addy-panicked-and-confused](http://www.hemophiliafed.org/news-stories/2020/03/dear-addy-panicked-and-confused)

COBRA & The ACA

[www.hemophiliafed.org/news-stories/2015/02/dear-addy-cobra-and-the-aca](http://www.hemophiliafed.org/news-stories/2015/02/dear-addy-cobra-and-the-aca)

Small Business Health Options Program (SHOP)

<https://www.hemophiliafed.org/news-stories/2014/05/dear-addy-shop>

Employee Disclosure:

[www.hemophiliafed.org/news-stories/2017/01/dear-addy-workplace-disclosure](http://www.hemophiliafed.org/news-stories/2017/01/dear-addy-workplace-disclosure)

[www.hemophiliafed.org/news-stories/2014/03/dear-addy-employee-disclosure](http://www.hemophiliafed.org/news-stories/2014/03/dear-addy-employee-disclosure)

## HFA DATELINE MAGAZINE

Transitioning to Adulthood: Voices from the Community

[https://www.hemophiliafed.org/dateline/HFA\\_Dateline\\_2014\\_Q4\\_Winter/HFA\\_Dateline\\_2014\\_Q4\\_Winter.pdf](https://www.hemophiliafed.org/dateline/HFA_Dateline_2014_Q4_Winter/HFA_Dateline_2014_Q4_Winter.pdf)

In this Dateline article (page 22), young adults share their tips on disclosure and self-advocacy in the workplace and at school.

## LA KELLEY COMMUNICATIONS

LA Kelley Communications was founded in 1990 with the belief that any individual facing hardship, adversity or challenges-when given the right tools-can overcome, triumph, and even grow stronger in character and confidence.

Parent Empowerment Newsletter (PEN), The Jobs Journal

[https://www.kelleycom.com/wp-content/uploads/2018/06/PEN\\_November\\_2012.pdf](https://www.kelleycom.com/wp-content/uploads/2018/06/PEN_November_2012.pdf)

2012 publication focused on employment and job skills for people with a BD

## NHF HEMAWARE MAGAZINE

The National Hemophilia Foundation publishes a quarterly magazine with information for people with bleeding disorders. The following links are articles related to employment issues.

Returning to Work After Having a Child with a BD

<https://hemaware.org/balancing-act>

Career Decisions for Teens with Bleeding Disorders

<https://hemaware.org/life/career-decisions-teens-bleeding-disorders>

## NHF STEPS FOR LIVING

Your Rights as an Employee

<https://stepsforliving.hemophilia.org/step-out/workplace-issues/your-rights-as-an-employee>

This article includes animated videos about accommodation and disclosure.

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## AMERICANS WITH DISABILITIES ACT (ADA) & ACCOMODATIONS

### ADA LAW

ADA.GOV Resource Page

[https://www.ada.gov/ada\\_intro.htm](https://www.ada.gov/ada_intro.htm)

Includes regulations, design standards, and a guide for filing a complaint under the ADA

ADA, The Full Law

[https://www.ada.gov/2010\\_regs.htm](https://www.ada.gov/2010_regs.htm)

Includes additional information about Title II (State and Local Governments), Title III (Public Accommodations and Commercial Facilities), and ADA Standards for Accessible Design

(<https://www.ada.gov/regs2010/2010ADAStandards/2010ADASTandards.htm>)

ADA Amendments Act Of 2008 (ADAAA)

<https://www.eeoc.gov/statutes/notice-concerning-americans-disabilities-act-ada-amendments-act-2008>

Overview of changes signed into the Act by the President on September 25, 2008 with a goal of making it easier for an individual seeking protection under the ADA to establish that they have a disability within the meaning of the ADA

ADA and Persons with HIV/AIDS

<https://www.ada.gov/hiv/>

Persons with HIV disease, either symptomatic or asymptomatic, have physical impairments that substantially limit one or more major life activities and thus are protected by the ADA

## JOB ACCOMMODATIONS NETWORK (JAN) RESOURCES

Overview of the ADA

[https://askjan.org/articles/The-Americans-with-Disabilities-Act-A-Brief-Overview.cfm?cssearch=1946925\\_1](https://askjan.org/articles/The-Americans-with-Disabilities-Act-A-Brief-Overview.cfm?cssearch=1946925_1)

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. This site includes a quick overview of each of the five titles, as well as an updated definition of who would qualify as disabled.

Accommodations for Individuals with Bleeding Disorders

<https://askjan.org/disabilities/Bleeding-Disorder.cfm>

Includes publications about accommodating employees with bleeding disorders, overview of types of limitations individuals with bleeding disorders might experience, and questions for employers to ask specific to bleeding disorder accommodation

Employees' Practical Guide To Requesting And Negotiating Reasonable Accommodation

<https://askjan.org/publications/individuals/employee-guide.cfm>

Summary of some of the most frequent issues that employees have regarding accommodations and ADA compliance. Available in PDF or DOC format

## U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION RESOURCES

Disability Discrimination

<https://www.eeoc.gov/disability-discrimination>

Provides information about Disability Discrimination and:

- Work Situations
- Harassment
- Reasonable Accommodation
- Reasonable Accommodation and Undue Hardship
- Applications, Interviews, and Job-Related Medical Exams

Employer-Provided Leave

<https://www.eeoc.gov/laws/guidance/employer-provided-leave-and-americans-disabilities-act>

Document that seeks to provide general information to employers and employees regarding when and how leave must be granted for reasons related to an employee's disability in order to promote voluntary compliance with the ADA

EEOC Field Offices

<https://www.eeoc.gov/field-office>

Find the EEOC Field Office closest to you by entering in your zip code. There are 15 EEOC Districts in the U.S.

Signature Industrial Services Sued by the EEOC

<https://www.eeoc.gov/newsroom/signature-industrial-services-sued-eeoc-disability-discrimination>

Overview of lawsuit wherein the EEOC sued the Signature Industrial Services for illegally firing individuals because of their blood disorder

## DEPARTMENT OF LABOR ACCOMMODATIONS RESOURCES

Accommodations Overview

<https://www.dol.gov/odep/topics/Accommodations.htm>

Includes overview of accommodations related to physical changes, accessible and assistive technologies, accessible communication, and policy enhancements. Has additional resources linked for reasonable accommodations.

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## FAMILY AND MEDICAL LEAVE ACT (FMLA)

### INTRODUCTION TO FMLA

<https://www.nationalpartnership.org/our-work/economic-justice/fmla.html>

National Partnership for Women & Families is a non-profit, non-partisan 501(c)3 organization that helped draft the original Family and Medical Leave Act and continues work to safeguard and expand its protections.

### GUIDE TO THE FAMILY AND MEDICAL LEAVE ACT (FMLA) QUESTIONS AND ANSWERS

<http://www.nationalpartnership.org/research-library/work-family/fmla/guide-to-fmla.pdf>

This guide from 2016, in its 8<sup>th</sup> edition, answers common questions about FMLA.

## FMLA OVERVIEW AND DOWNLOADABLE MATERIALS

<https://www.dol.gov/agencies/whd/fmla>

FMLA entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons. Department of Labor (DOL) website includes:

- Overview <https://www.dol.gov/general/topic/benefits-leave/fmla>
- Fact Sheets <https://www.dol.gov/agencies/whd/fact-sheets/28-fmla>
- Posters <https://www.dol.gov/agencies/whd/posters/fmla>
- FAQ <https://www.dol.gov/agencies/whd/fmla/faq>
- E-Tools
- Forms
- Interpretive Guidance
- Applicable Laws and Regulations

## HOW TO FILE AN FMLA COMPLAINT

<https://www.dol.gov/agencies/whd/contact/complaints>

Overview information, investigative process, FAQ, Reference Cards, and English/Spanish Documents

- English Document:  
<https://www.dol.gov/sites/dolgov/files/WHd/legacy/files/WHd1498HowToFileAComplaint.pdf>
- Documento Español:  
[https://www.dol.gov/sites/dolgov/files/WHd/legacy/files/WHd1498HowToFileAComplaint\\_Spanish.pdf](https://www.dol.gov/sites/dolgov/files/WHd/legacy/files/WHd1498HowToFileAComplaint_Spanish.pdf)

## STATE FAMILY AND MEDICAL LEAVE LAWS

<https://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>

FMLA allows states to set standards that are more expansive than the federal laws and many states have chosen to do so. This website provides a table to show the statutory provisions of states with their own family leave laws.

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## JOB SEARCH RESOURCES

### CHRONICALLY CAPABLE

<https://www.wearecapable.org/>

Chronically Capable is an employment platform that connects chronically ill professionals to companies looking to hire a digital workforce and meet the 7% utilization goal required under Section 503 of the Rehabilitation Act.

### FLEXJOBS

<https://www.flexjobs.com/About.aspx>

Flexjobs curates every job and company they list to ensure they are professional jobs (all levels), have flexible options, high quality listings, and a satisfaction guarantee for site users. You can search by location using the Flexjobs map: <https://www.flexjobs.com/searchLocation>

## JOB-SEEKING TIPS AND EMPLOYMENT RIGHTS FOR JOB-SEEKERS AND EMPLOYEES (JAN)

<https://askjan.org/info-by-role.cfm#for-individuals:employees>

Tips and information about how to access JAN free consulting services for all individuals, regardless of employment status, as well as a list of online tools, publications and resources

## JOB CHOICE FROM NHF STEPS FOR LIVING

<https://stepsforliving.hemophilia.org/step-out/workplace-issues/job-choice>

Step-by-step process on how to make the right career choice

## STATE VOCATIONAL REHABILITATION AGENCIES

<https://askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm>

By contacting your local vocational rehabilitation office, you will tap into a wealth of resources related to employment options for people with disabilities. JAN lists offices' websites and contact information, organized by state.

## USAJOBS – INDIVIDUALS WITH DISABILITIES

<https://www.usajobs.gov/Help/working-in-government/unique-hiring-paths/individuals-with-disabilities/>

Information to help people with disabilities find a government job, develop work skills, get support with job-seeking, or find an education program

## DISABILITY RESOURCES FROM U.S. DEPARTMENT OF LABOR

<https://www.dol.gov/general/topic/disability>

The Department of Labor assists people with disabilities in seeking meaningful work and succeeding once on the job, and advises employers on effective strategies for recruiting and retaining qualified people with disabilities. This site also provides information on:

- Office of Disability Employment Policy
- Office of Federal Contract Compliance Programs
- Office of the Assistant Secretary for Administration and Management, Civil Rights Center (CRC)
- Employment and Training Administration
- U.S. Department of Education

## LAUNCH VOCATIONAL JOB TRAINING ASSISTANCE PROGRAM

<https://hfmich.org/>

This program, created by the Hemophilia Foundation of Michigan, that provides support to individuals as they pursue academic completion, certification training and improved job placement. Contact Anthony Stevens at [astevens@hfmich.org](mailto:astevens@hfmich.org) for more information.

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## JOB INTERVIEWS

### OFFICE OF DISABILITY EMPLOYMENT POLICY – YOUTH, DISCLOSURE, AND THE WORKPLACE WHY, WHEN, WHAT, AND HOW

<https://www.dol.gov/odep/pubs/fact/ydw.htm>

Informative article with additional resources from the National Collaborative on Workforce and Disability for Youth

### BENEFITS PACKAGE FROM NHF STEPS FOR LIVING

<https://stepsforliving.hemophilia.org/step-out/workplace-issues/benefits-package>

Once you've been offered a job—or when you change jobs—look carefully at the benefits package being offered.

### HFA YOUNG ADULT HANGOUT ON BUSINESS BASICS: THE DOS AND DON'TS FOR CAREER SUCCESS

<https://www.youtube.com/watch?v=ogFqdaXmks>

Elizabeth DeGrandpre shares tips for landing and keeping a job, phone interviews, nonverbal communication, networking, professional email, social media presence, creating a resume when you have no job experience, and how to tailor a resume and cover letter to a job. (12/20/17)

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## RESOURCES FOR SELF-ADVOCACY

### WEBSITES & SERVICES

Patient Services Inc (PSI)'S A.C.C.E.S.S Program

<http://www.patientservicesinc.org/For-Patients/ACCESS>

PSI's ACCESS helps families navigate state and federal entitlement programs and provides a legal support hotline to assist with workplace and health insurance issues.

The Chronic Illness Career Coach

<https://cicoach.com/>

Rosalind Joffe ([rosalind@cicoach.com](mailto:rosalind@cicoach.com)) specializes in working with professionals living with chronic health conditions who want to continue to thrive, not just survive. Services and resources include career coaching, newsletter, guidebook, workbook, and more.

But You Don't Look Sick

<https://butyoudontlooksick.com/>

Christine Miserandino is a woman living with Lupus. Her website provides resource articles, book and product reviews, health resources, and information about her “Spoon Theory.”

Legal Metro: Rights of the Disabled

<https://www.legalmetro.com/library/rights-of-the-disabled>

Links to legislation, advocacy groups, organizations, and initiatives regarding the rights of people with disabilities

Workplace Fairness

<https://www.workplacefairness.org/>

Workplace Fairness is a nonprofit working to preserve and promote employee rights. They believe that fair treatment of workers is sound public policy and good business practice. The site offers free information about workers’ rights that avoids legal jargon.

## ARTICLES

Chronic Illness and The Future of Work - Forbes

<https://www.forbes.com/sites/manondefelice/2019/09/04/the-surprising-truth-about-chronic-illness-and-the-future-of-work/#6d3374ff3e38>

Discusses the experiences of Hannah Olson, who had to quit her dream job because of the challenges of balancing it with her chronic Lyme’s Disease. Hannah then started her own company called Chronically Capable (<https://www.wearecapable.org/>) to assist individuals who are chronically ill to find flexible jobs.

How to Manage Work When You Have a Chronic Illness - Glassdoor

<https://www.glassdoor.com/blog/chronic-illness/>

Article from 2017 by Sheiresa Ngo with resource websites and books listed at the end.

What It's Like Living and Working With a Chronic Illness - The Muse

<https://www.themuse.com/advice/working-living-with-a-chronic-illness>

This personal essay, written by Alex Haagaard, discusses the author’s experience learning how to manage her illness with a variety of approaches, finding the right accommodations, and building a support structure at work.

Minding the Resume Gap - Cancer and Careers

<https://www.cancerandcareers.org/en/looking-for-work/resume-cover-letter/resume-gap>

Article that targets cancer survivors, but can still be a helpful resource for the bleeding disorders community in acknowledging gaps in employment due to one’s medical condition both on the resume and in an interview

How to Achieve Your Goals at Work While Dealing with Chronic Illness -Girlboss

<https://www.girlboss.com/read/working-with-chronic-illness>

Article from 2018 that includes strategies that the author found to be helpful while juggling work and health

Living with Chronic Illness: Finding a Job that Works for You - Idealist

<https://www.idealist.org/en/careers/chronic-illness-finding-job>

Article from 2019 written by Nisha Kumar Kulkarni about working with chronic illness, finding the right job, and prioritizing your health

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## EMPLOYMENT DATA

CDC STATISTICS ON CHRONIC HEALTH IN THE US

<https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm>

Goals of CDC studies include:

- Finding out how chronic diseases affect populations in the United States
- Studying interventions to find out what works best to prevent and control chronic diseases
- Funding and guiding states, territories, cities, and tribes to use interventions that work
- Sharing information to help all Americans understand the risk factors for chronic diseases and how to reduce them

HFA CHOICE Survey

<https://www.hemophiliafed.org/for-patient-families/participate-in-research/results-of-choice/>

The CHOICE Project was the first of its kind in which the Centers for Disease Control and Prevention (CDC) asked patients, not their providers, to report directly on their health outcomes. Two resources that were initiated by the Hemophilia Federation of America (HFA) as a result of this Survey were:

- Blood Sisterhood Program: Increases advocacy and programming for females with bleeding disorders
- Project CALLS (Creating Alternatives to Limiting and Lacking Services): collects stories from the bleeding disorders community to identify trends and build cases for changes in insurance issues

HERO (Hemophilia Experiences, Results, And Opportunities) Study

<https://ashpublications.org/blood/article/120/21/4244/86646/Hemophilia-Experiences-Results-and-Opportunities>

The HERO Initiative was developed to increase understanding of the psychosocial issues impacting people with moderate-severe hemophilia.

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