

Supporting NF Employees

A Toolkit for Inclusive Workspaces



SEVENTEEN22
FOUNDATION

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ALEXION[®]
AstraZeneca Rare Disease

About the Seventeen22 Foundation

WHAT IS NF?

Neurofibromatosis (NF) is a genetic disorder of the nervous system which causes tumors to form on the nerves anywhere in the body at any time. This progressive disorder affects all races, all ethnic groups and both sexes equally. NF is one of the most common genetic disorders in the United States (one in every 2,000 births). The neurofibromatosis affects more than 4 million people worldwide.

NF has genetically distinct forms: NF-1 and schwannomatosis, which includes NF-2 related schwannomatosis. They are caused by different genes and chromosomes. The effects of NF are unpredictable and have varying manifestations and degrees of severity. There is no known cure for any form of NF, although the genes for both NF-1 and schwannomatosis have been identified.

OUR MISSION

Provide assistance to families impacted by neurofibromatosis.

OUR VISION

To provide programs and advocacy for families affected by neurofibromatosis so the families can concentrate on the things that matter, their loved ones.

OUR PROGRAMS

- Family Aid Grants - Assistance up to a specified amount per year to help families with expenses associated with neurofibromatosis that are not covered by insurance or other third party providers.
- Birthday Celebrations - Provides a birthday box to an individual with NF during their birthday month.
- PJ's for the Holidays - Provides pajamas to NF families during the holiday season.
- Katelyn & Kylie Earle Scholarship - A scholarship fund dedicated to individuals affected by neurofibromatosis and their siblings.
- NF Family Pathways - Provides direct patient support to help navigate the healthcare system and education.



Adults with NF have a lower employment rate compared to the general population, with an odds ratio (OR) of 0.71 for employment at age 30.



Workplace bullying is reported at 13% among NF employees, compared to 5% in the general workforce.



NF employees are more likely to find work physically exhausting (74%) compared to non-NF employees (44%).



Pain and discomfort are major workplace challenges, with 40% of NF1 employees reporting moderate to extreme pain



Anxiety and depression are prevalent, affecting 51.4% of NF1 employees, which can influence workplace engagement.

Sources:

<https://ojrd.biomedcentral.com/articles/10.1186/s13023-023-02965-2>
<https://academic.oup.com/occmed/article-abstract/69/7/504/5610894?redirectedFrom=fulltext>



Advocating for yourself in the workplace as a neurofibromatosis patient can be challenging, but with the right strategies, you can create a supportive and accommodating environment. Here are some key tips:

1. Define Your Needs

- Identify specific challenges you face in the workplace due to your condition.
- List accommodations that would improve productivity and well-being.
- Consider both formal (ADA-protected) and informal adjustments

2. Prepare Your Communication Strategy

- Develop a concise explanation of NF and how it impacts your work.
- Craft talking points for discussing accommodations with your employer.
- Decide whether to share broadly with colleagues or selectively.

3. Leverage Policies and Resources

- Review your company's existing accommodations policies and disability support.
- Use external resources, like rare disease advocacy groups and the Seventeen22 Foundation, to strengthen your case.

4. Build Allies and Networks

- Connect with HR for guidance.
- Seek mentors or allies who can advocate alongside you.
- Engage with broader rare disease communities for support.

5. Document Everything

- Keep records of accommodation discussions and agreements you have made.
- Track workplace challenges and how adjustments impact your work.
- Maintain communication logs for accountability.

Workplace Recommendations for the Employer

Workplace Adaptations for NF Enhance Productivity & Retention

- NF symptoms vary, but common workplace challenges include pain management, fatigue, mobility limitations, and medical appointments.
- Allowing flexible schedules or remote work helps NF employees maintain productivity without compromising health.
- Employees who feel supported are more likely to stay long-term, reducing turnover costs.

Cost Effective NF Accommodations

- Many adjustments require little to no expense:
 - Allowing ergonomic seating, temperature control, or low-stimulation environments for sensory sensitivities.
 - Break adjustments for pain management or fatigue.
 - Access to assistive technology for those experiencing nerve-related motor difficulties.
- The Job Accommodation Network (JAN) confirms that most accommodations cost employers nothing or under \$500.

NF Advocacy Aligns Workplace Inclusivity

- Since NF is a rare, often invisible condition, normalizing discussions about invisible disabilities strengthens inclusivity.
- Companies committed to equity in healthcare support set themselves apart as top-tier employers.
- Representation matters—supporting NF employees fosters a more diverse and empathetic workforce culture.

Legal Protections & ADA Compliance for NF

- NF qualifies under the ADA's definition of disability, ensuring access to workplace accommodations.
- Employers who proactively support employees with NF reduce legal risks and demonstrate ethical leadership.
- Providing clear accommodation processes ensures compliance while enhancing workplace morale.

NF Education Creates a More Understanding Workplace

- Brief awareness initiatives (e.g., NF facts in employee newsletters or internal training) increase understanding and empathy.
- Highlighting workplace accommodations for NF demonstrates commitment to employee well-being.
- Encouraging open conversations reduces stigma, allowing employees to feel heard.



Thank You

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