



Disability & Migraine Disease

A Policy Panel Discussion



Introduction

How can America's workplaces empower people living with migraine disease to sustain meaningful employment?

A 2019 Capitol Hill policy panel convened by The Headache & Migraine Policy Forum brought together patients, health care providers, advocates and policymakers to consider this and related questions on migraine disease, disability and employment in the United States. The event coincided with the 12th annual Headache on the Hill congressional advocacy event, organized by the Alliance for Headache Disorders Advocacy.

Former U.S. Rep. Tony Coelho, pictured below, delivered the event's keynote address.

"You're all covered by the [Americans with Disabilities Act]," Mr. Coelho announced to a crowded room of headache advocates. "I know," he emphasized, "because I wrote it."

The former representative from California has dealt with epilepsy throughout his life, spurring his leadership on disability issues. He authored the landmark Americans with Disabilities Act while serving in Congress and today chairs the advocacy group Partnership to Improve Patient Care. Mr. Coelho shared his past struggles and encouraged the advocates present to use their own stories to spur members of Congress to ensure adequate protections for people with disabilities.

As Alliance for Patient Access Chairman David Charles, MD, noted in his opening remarks, the Americans with Disabilities Act has been a watershed. The U.S. Census reports that roughly 800,000 more people with disabilities have joined the country's workforce as a result of the bill, which was signed into law in 1990 by President George H.W. Bush.



In the policy panel discussion that followed, experts considered the impact of workplace accommodations—or lack thereof—on people living with migraine disease. Panel participants included:



Sara Van Geertruyden

Executive Director,
Partnership to Improve
Patient Care



Angie Glaser

Advocate; Content Editor,
“Migraine Again”



Michael Gamel-McCormick

Disability Policy Director,
Office of U.S. Sen. Bob Casey



Stacey Worthy, J.D.

Counsel, Aimed Alliance



Their dialogue made several points clear:

1

Without appropriate accommodations, people living with migraine disease struggle in their work environments.

Panelist Angie Glaser recalled the challenges of her past employment endeavors, which lacked the necessary accommodations for people who, like Angie, live with migraine. Migraine attacks left Glaser nauseated, fighting both blurred vision and the feeling that her brain was “in a bowl of water.” Symptoms cut her 40-hour workweek short. That meant using weekends to catch up on work and taking vacation days to recover from attacks.

“My manager was not unkind,” Glaser recalled, “but she didn’t know how to help me.”

2

Workplace accommodations for employees with headache disorders and migraine disease can be simple—and life-changing.

Today there are straightforward changes that employers can make to help their staff living with migraine disease. Stacey Worthy, counsel to the Aimer Alliance, named just a few.

“Anti-glare shields for computer screens; fragrance-free workplaces; putting people with migraine in less congested, quieter areas; telecommuting,” Worthy explained. She called on employers to create a friendly workplace where people with migraine disease feel comfortable, to “find something that works for everyone.”

Doing so can improve the lives of employees with migraine, giving employers a more diverse, productive workforce and helping to reduce the wage gap since migraine disease disproportionately affects women during their peak earning years.



3

Federal policies can encourage employment and quality of life for people living with migraine disease.

Tax incentives exist for employers who hire and retain people with disabilities. But, as Michael Gamel-McCormick, disability policy director for Sen. Bob Casey explained, these are often underused. New legislation aims to incentivize more employers by increasing existing tax credits. The Disability Employment Incentive Act, authored by Sen. Casey, would enhance three existing tax credits, including credits for employers who make their physical and online workspaces more accessible to people with disabilities.

Members of Congress are also working to increase financial stability for people with disabilities through the ABLE Age Adjustment Act. ABLE (Achieving a Better Life) Accounts allow people with disabilities to put aside money, tax-exempt, for disability-related expenses. This allows people with migraine disease to cover disability's hidden costs, such as special glasses or certain foods that don't trigger a migraine attack, without surpassing the income cap that comes

with receiving Social Security Disability Insurance or Supplemental Security Income benefits. The bill would expand account eligibility to people who have developed a disability by age 46.

4

The Social Security Administration should clarify its processes.

For people with migraine disease who have no choice but to leave the workforce, the Social Security Administration must reform its process for claiming Social Security Disability Insurance or Supplemental Security Income. Currently, people with migraine disease are asked to compare their impairments to non-migraine impairments listed in the Social Security "Blue Book." They need clear guidance on how to complete this evaluation process fairly and appropriately. They would also benefit from a Blue Book listing that's specific to migraine and headache disorders.





Congressional Remarks

The morning's event culminated with an award from the Alliance for Headache Disorders Advocacy to **U.S. Rep. Andy Harris, M.D.**, an anesthesiologist and representative from Maryland who has battled cluster headaches since he was in medical school.

"I know exactly where I was the first time I got a cluster headache," Rep. Harris recalled. He described

how the disorder has plagued him for 25 years, and he expressed his camaraderie with fellow migraine and headache patients in the room.

"[Members of Congress] have to do everything we can," he emphasized, adding, "I'll be there with you every step of the way."

Rep. Harris is the first member of Congress to speak publicly about his personal experience living with the disease, marking an important step in the effort to destigmatize headache disorders.



Policy Recommendations

Employers can:

- Provide necessary and appropriate accommodations for people living with migraine disease.
- Use tax incentives to make both physical and online work environments accessible to people with disabilities.

Members of Congress can:

- Pass the Disability Employment Incentive Act to expand federal incentives to America's employers.
- Pass the ABLE Age Adjustment Act to increase the number of people with disabilities who can use tax-exempt accounts to cover disability-related expenses.

The Social Security Administration can:

- Issue a ruling to guide people with migraine disease on how to best compare their migraine impairments to non-migraine impairments when applying for Social Security Disability Insurance or Supplemental Security Income.
- Assure that all Blue Book listings are never five years past their last review.
- Add a Blue Book listing specifically for impairments that arise from migraine disease and headache disorders.



The Headache and Migraine Policy Forum advances public policies and practices that promote accelerated innovation and improved treatments for persons living with headache disorders and migraine disease.



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