



## Vestibular Disorders Association



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# **Vestibular Disorders Association — Comments to the Social Security Administration about Evaluation and Disability Determination for Vestibular-Labyrinthine Dysfunction**

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## INTRODUCTION

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In mid-April 2005, the Social Security Administration (SSA) asked the Vestibular Disorders Association (VEDA) to submit comments and suggestions on the rules that the SSA uses to evaluate hearing and vestibular disorders in adults and children who apply for, or receive, Social Security disability benefits or Supplemental Security Income (SSI) payments based upon disability, as well as related return-to-work issues. VEDA invited its several thousand members (comprising health professionals and people with vestibular disorders) to submit comments that VEDA could compile and present to the SSA.

VEDA's announcement to members appeared in its Spring 2005 newsletter, *On the Level* (Vol. 22, No. 2). In an effort to help members comply with the SSA's posting guidelines for focused responses, VEDA posed questions for members to consider as they framed their responses. Members were not, however, restricted to addressing these questions.

The following report summarizes the responses submitted by VEDA members and is organized by the questions posed in the newsletter. Many direct quotations from members are included. Although the response rate was relatively low (VEDA is aware that many individuals with vestibular disorders experience increased symptoms when they address paperwork), the comments submitted were both insightful and relevant to the important issues under consideration.

This report includes responses from both medical professionals and people with vestibular disorders. Several responses came from medical professionals who have personally experienced a vestibular disorder. Although one respondent is a member of VEDA's Board of Medical and Scientific Advisors, the opinions expressed throughout this report are not necessarily those of VEDA's advisors, nor of its Board of Directors or staff. The response time allowed for this information-gathering phase by the SSA was too short for VEDA's Board of Medical and Scientific Advisors to review the comments presented below.

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## SUMMARY

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Some general perceptions and observations that emerged from the responses:

1. There is a broad lack of understanding about vestibular disorders in the SSA.
2. The SSA's diagnostic and evaluation criteria are outdated and inaccurate.
3. The disability-determination criteria ignore common and important functional limitations resulting from the symptoms and secondary effects of chronic vestibular disorders.
4. The complexity and lengthiness of the disability-determination process, in combination with the difficult symptoms of a vestibular disorder, requires the person to seek assistance with the application process and may impede attempts to return to sustainable work.

One member who wrote a lengthy response, included at the end of this report under "Five Steps to Help Vestibular Patients Return to Work" (p. 11), summed up the remarks of many in the following paragraph:

"I think the critical question SSA should be asking about their system and procedures is, 'How can we get the vestibular-disabled patient onto disability smoothly and quickly without making them worse?' If these procedures are not streamlined for vestibular-challenged people, the time and effort it takes the person to apply for SSA can cause increased vestibular problems and side effects that decrease their ability to work later. Help the truly vestibular-compromised patients get onto SSA and Medicare so they can spend more of their already compromised energy getting treatments and rehabilitation and adapting to this disease, so they can go back to work."

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## VEDA MEMBERS' COMMENTS AND SUGGESTIONS TO THE SSA

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The responses that VEDA received are given below, organized according to the questions posted in Vol. 22, No. 2 of VEDA's newsletter, *On the Level*. Comments and suggestions that were submitted as part of a personal narrative have been placed under the most relevant question area. For questions that elicited multiple similar responses, a representative selection of comments is presented.

### Questions for VEDA members — Especially health professionals

**Question 1: Should the diagnostic criteria in the listings be changed?**

**Question 2: Should the medical criteria for evaluation of impairment be changed?**

All who responded to these two questions indicated that the current SSA disability-determination rules do not accurately reflect the range of vestibular disorders, current diagnostic and medical criteria, and/or recognition of balance impairment.

Comments from a physician specializing in vestibular disorders (this physician's remarks are given here in full):

The SS rules shown on page 10 [of *On the Level*] are very old and should be updated.

Paragraph 1: "or loss of position sense" — has nothing to do with Ménière's disease. This is just a mistake. It might be worth mentioning drop attacks as a symptom too, as this is particularly disabling.

Paragraph 2: OK.

Paragraph 3: "neuro-otolaryngologic" should be "neuro-otologic."

"Bekesey audiometry" should be replaced by "ECOG testing" or nothing; nobody does Bekesey anymore.

"Polytomograms, contrast radiography" should be replaced by "Neuroradiologic testing."

"in addition to appropriate medically acceptable ..." should be eliminated — MRI has replaced X-rays.

Delete "myelography and radionuclear bone scans" — they have no role in Ménière's disease.

Impairment of balance should be recognized.

Comments from a physician who has a vestibular disorder:

"I am commenting specifically on the inadequacies of the current rules as applied to a central vertigo. Although the first sentence of [the SSA] rules correctly defines vertigo, the last sentence of the same paragraph gives the implication that a rotatory component is necessary to support 'vertigo,' which is incorrect. A central vertigo (mal de débarquement, for example) may have little in objective findings both on physical exam and available testing. The diagnosis is based on history, and the degree of disability is also based on history. That needs to be stressed in the 'rules.' There may be tests in the future that will help support a diagnosis of central vertigo, such as posturography ... Sometimes neuropsychiatric studies are helpful, as there are certainly cognitive impairments seen; but [neuropsychiatric

studies] are labor-intensive and would be better listed as a suggestion, not a requirement.”

Comments from other VEDA members:

- “A patient can experience symptoms of dizziness, vertigo, and/or imbalance even while *sitting* or in a sedentary position (even lying in bed) ... These symptoms do not have to be provoked with the action of standing or walking or any other movement.

Also, I disagree with Part III, Part A, Section 2.00, which states that for diagnosing Ménière’s disease, ‘the severity of impairment is best determined after prolonged observation and serial reexaminations.’ It’s quite possible for people to have had many years of symptoms related to Ménière’s disease, although remain undiagnosed or misdiagnosed. For the patient who is having severe attacks who may finally receive a diagnosis or receive a correct diagnosis, he/she should not have to suffer unnecessarily by delaying the application for disability so that a physician can have ‘prolonged observation and serial reexaminations’ of the patient. This period of ‘prolonged observation’ is vague at best and should be eliminated from the diagnostic criteria.”

- “The BSER (brain stem evoked responses test) and the rotational chair test should also be diagnostic tools.”
- See also “Five Steps to Help Vestibular Patients Return to Work” (p. 11), no. 5.

### **Question 3: Should the rules acknowledge that a person without hearing loss can have disabling vestibular dysfunction?**

Those who responded to this question indicated that hearing loss may or may not accompany some types of vestibular disorders, so the absence of hearing loss should not exclude disability.

- “Lack of hearing loss does not indicate that all is well with the vestibular system.”
- “The rules should absolutely be changed so that a person with a disabling vestibular dysfunction does *not* need to experience hearing loss ... Disabling vestibular dysfunction can be the result of injuries to the inner ear, whether viral or traumatic (e.g., car accident) that do not necessarily impact one’s hearing.”

### **Question 4: What percentage of disabling labyrinthine-vestibular cases in your practice would the current SSA listings likely miscalculate?**

VEDA did not receive any direct responses to this question.

**Question 5: To what extent does the prolonged disability-determination process characteristic of the SSA's program hinder or impede long-term resolution of symptoms? Could such continuation of symptoms be due in part to delays in receiving treatment? Support services? Does the stress of a prolonged disability-determination process sometimes exacerbate the medical condition?**

- "The process exacerbates the symptoms and may delay the patient's access to appropriate specialized care."
- "Definitely yes ... they wonder how they are going to live financially and they *know* they *can't* work!"

**Question 6: Should a listing be included for disturbance of labyrinthine-vestibular function in children? If such dysfunction is not addressed with early treatment and support, how might this impact a child's long-term functioning?**

- "If this is not addressed with early treatment and support, this could have a negative impact on a child's life, self-esteem, self-confidence and self-worth."

Questions for VEDA members — Especially those who have applied or might apply to the SSA

**Question 1: What do you think is the most difficult or stressful part of the disability-determination process?**

- "Without a doubt, the most stressful part for me is that the SSA does not understand vestibular disorders. I have had to become my own advocate and educate my disability holder and they are very grateful for the materials I provide to them. That is tough or almost impossible to do with a government agency ... Our healthcare system (including SSA) is not geared to serve the chronically ill population in an effective manner that meets the needs of the client, the medical provider, or even SSA. A major re-invention of thought, process, and provision needs to be implemented to do this."
- "I also had polio ... This gives me a chance to compare the rehab needs of someone with polio and someone with a vestibular disorder ... I think Social Security and Vocational Rehab need to do a better job of determining when a person with a vestibular disorder is able to work, what kind of work that person can do, and offer more help in finding an appropriate job. A person with a vestibular disorder needs more attention from their rehab counselor than most clients do. I found it much easier to work or go to school after I had polio than I did after I developed a vestibular disorder.  
Social Security sent me to a class at Goodwill to help me develop job hunting skills. I already had a degree in education, had been a teacher for five years, and a computer programmer for 4 1/2 years. I don't think that class really offered me the kind of help I needed.  
Social Security also sent me to Vocational Rehab. The counselor I had seemed to be more interested in people getting out of jail than in people with disabilities.

My suggestion is that a rehab counselor should work intensively with a vestibular patient until he/she has found a job and follow that person for at least two years after they go to work.

A person may need work near home because they can neither drive nor ride a bus any distance.

A rehab counselor needs to do more than send a person to the unemployment office to find a job. The rehab counselor may need to contact the employer to determine if a job is suitable. Most people don't have to worry about noise levels, fluorescent lighting, and whether they can make it through the day or not. Those of us with vestibular problems do have to worry about some or all of those things. Interviewing for many jobs is stressful for anyone but particularly difficult for someone with a vestibular disorder."

- "The length of the waiting process is brutal when it is the sole avenue for income; the seeming 'automatic' denials are frustrating even when medical documentation has been provided, requiring the assistance of costly legal counsel. Also, not knowing if the SSA person reviewing the medical records is a specialist in the field of vestibular dysfunction. [Being able to] afford to seek the proper medical attention required to satisfy the SSA's criteria within their timeframes ... the SSA physician I was required to see seemed quite detached and only performed a hearing test, ignoring all other aspects of vestibular problems and their daily impact and limitations."
- "All the paperwork ... having to speak to someone on the phone when you have low hearing and you cannot tilt your head for fear of having an attack ... being patient while they put you on hold and listen to noises in the background which are making you nauseated ... 'The forms are on the internet,' I am told by SSA, but because I have visual issues with the computer I have to get someone else to fill them out ... Gathering information from doctors who most likely do not have your records anymore because they have moved or have changed computer systems."
- "When you can't even get a doctor to understand and most friends, how on earth can someone at SSA or SSS even have a clue?"
- "I had an attack in the [SSA] office where I applied. The agent wrote in her report I was unable to walk without her assistance and they rejected me. Then 11 months later I finally got a time before a Judge ... I had to be driven 45 miles to this and I had started an attack earlier in the day so when the Judge saw me ... it took him only 10 minutes to believe [I] cannot function. What a waste of Tax Dollars!  
They need better qualified staff to understand vestibular conditions in that you can function fine one minute and [not] the next; that is unpredictable. If an individual does not have Long Term Disability, you would go homeless by the time you get your benefits. My process took 28 months."
- See also "Five Steps to Help Vestibular Patients Return to Work" (p. 11), no. 3.

**Question 2: What aspects of vestibular disorders do you think are not considered, but should be, in the SSA's determination of disability?**

The most common elements mentioned were the cognitive impacts of vestibular disorders and environmental factors that are difficult to control but that aggravate symptoms in public places, work environments, and the home.

- "The cognitive impact; also the environmental aspects such as surroundings, crowds, noise, weather conditions, etc. ... The exertion required to complete simple tasks cannot be clearly defined by a yes or no answer, and symptoms are difficult to describe."
- Sensitivity to work conditions (such as noise, lighting, vibrations, Venetian blinds). "It takes me quite some time to adjust to a new work space ... I am affected by motion and vibrations. So for example, if you are on the second floor of a building, the person next to you or someone else walking hard on the floor vibrates it; how do you get around the nausea? ... I am affected by all weather changes, including wind, rain, fronts, snow, humidity, etc."
- "The SSA list of symptoms is heavily weighted to acute attacks and is probably based on an understanding of Ménière's disease, rather than the broader list of more common vestibular issues." With chronic vestibular disorders, "symptoms do wax and wane. The increase of symptoms is most often due to activity levels, with crowd exposure a key factor. And most important, if I am exposed to crowds, travel, or other factors causing dizziness and nausea for several days in a row, the symptoms become severe and I am unable to function for a week or more. It is this repetitive pattern that prohibits employment. To think that a vestibular patient who is not having an acute episode can readily work is to ignore this pattern.  
In addition, the SSA does not appear to recognize that typical interactions in a work environment — small meetings of 2-3 people, long periods of computer work, reading and any form of travel — are typical factors causing vestibular symptoms. My tolerance for these activities — which I believe is typical of a large segment of the VEDA membership — is about an hour at a time. It takes me several hours of non-stimulating activity to recover. It is difficult to impossible to structure employment around this limitation."
- "Your *whole* life style is changed." "Vision, anxiety, stress, and nausea" should be considered more strongly.
- "I have permanent nerve damage in my left ear ... I jar with every step I take because of the nystagmus, so my surroundings are constantly moving. I can accomplish some things, but at my own pace with lots of rest in between ... Because a person with balance problems looks normal, people assume you could work if you really wanted to. I can assure you that no one is going to get rich from Social Security, so I would rather be working. Unfortunately, that's not an option for me."
- "I don't believe the SSA takes into account the individual effects that a vestibular disorder has on each individual ... The aspects that need to be considered are the individual manifestations and level of disability that occur in vestibular patients. I have seen or read about some that have little or no long-term or functional effects, but my chronic illness has changed my life drastically."

**Question 3: Do you think your current level of impairment and work ability would be the same or different if the SSA's evaluation and determination processes were shorter and less stressful?**

The respondents to this question all more or less indicated that their level of impairment would likely remain the same if the process were improved, but that with less stress, they would be in the best possible condition for work (if they were able to work at all).

- "I believe if the SSA's evaluations and determinations process were shorter and less stressful, I feel I would have started the process a while ago when I was less sick, instead of aggravating my disease. I need to rest, and all I do is run around to doctors to get papers, make phone calls, and fill out papers ... I am a *safety* risk to the people on the highway, the people I work with and most of all myself." To remain in the workforce, there is a need to educate people daily about one's disease.
- "I believe my current level of impairment would be the same however, a shorter process would lessen the stress and sense of hopelessness considerably, hence opening up the 'brain space' needed to actually consider work ability and in what capacity."
- "The reevaluations are what I feel are so unfair ... My condition is permanent; and when they want reevaluations, I have to go through tests that bring my vertigo on again."
- See also "Five Steps to Help Vestibular Patients Return to Work" (p. 11), no. 2.

**Question 4: If you currently receive disability income from the SSA and would like to try returning to part-time or full-time work, does the length of the disability-determination process deter you, for fear of having to go through the process again if your attempt to work increases your symptoms to the point that you are unable to keep working? If so, how much shorter would the process have to be to encourage you to attempt working?**

Respondents generally indicated that such a deterrent was strong and the "cost" of repeating the process too high, despite their desire to work (for income, increased perception of self-worth, social acceptability, and other reasons).

- "I would feel more inclined to [explore working again] if I knew that I could return back on disability quickly and easily *without* having to start over and re-apply again."

**Question 5: What is the most important change in its programs that the SSA could make that would motivate you to explore work options to your full potential without feeling threatened by a loss of SSA income?**

- Provide "something in writing as a guarantee stating that any failure in attempting to perform any work would cause no interruption in benefits ... The idea of starting over is too intimidating."
- "SSA has to be more flexible ... It has to work with providers (PT, OT) to work on innovative programs to help people with vestibular disorders modify their lifestyles to be able to work. SSA can play a key part in the education of patients and providers if there were financial incentives. Those incentives would be getting people off the dole completely or at least back in the work force part time in a situation that is sensitive to their vestibular disorder. Right now, SSA is not informed on vestibular disorders, so they reject more applications based on lack of knowledge and incentive ... If I were not educated, had a successful career, etc. I would have an easier time getting SSI. I am penalized for having been successful. There isn't a lot of flexibility with SSA."

**Question 6: Do you think the SSA listings of impairments are difficult to understand and/or apply?**

- "Yes. A clearer definition is needed. Words like 'labyrinthine,' 'ataxia,' 'nystagmus,' and 'syncope' are not layman's terminology."
- "Absolutely!"
- "For me, having worked in healthcare and with government health and social agencies, it's not too difficult to understand. For the average person without that experience, it's enough to keep them from applying ... it needs to be simpler and easier to understand."
- "I really don't think doctors understand Social Security guidelines. My specialist felt that I could probably do some type of work a couple of hours on a good day. Try to find someone that will hire you to come to work when you are having a good day for a few hours. The doctors really didn't understand the question, 'Can he work a full day, five days a week?'"

**Question 7: Do the symptoms of your vestibular disorder affect your ability to understand and/or comply with the SSA's application requirements? If so, how might the SSA recognize and accommodate the limitations of your disability so that the application process is accessible to you throughout its duration? For example, should the SSA simplify the paperwork? Shorten the waiting period? Provide an SSA representative to assist you with the required paperwork?**

- "Yes, and I believe one's doctor/specialist should play a larger part in the process."

- From a physician with a vestibular disorder: "Most disability forms ask questions that are virtually impossible to answer when dealing with vestibular problems."
- "The paperwork needs to be simplified. [SSA representatives] in decision-making positions need to have a better understanding of what is involved with balance disorders. It needs to be on the list of recognized disabilities."
- "I found it very hard to keep appointments, as you don't know from one minute to the next how you are going to feel, let alone day to day, or week to week. If you feel bad, it's not easy to even talk on the phone." The waiting period should be "much shorter. [For] a person going through this, [it] is a nightmare; you *really* do think you are going crazy ... *Most important*, an SSA rep should assist you with all paperwork."
- SSA decision-makers should be well trained and should assist with paperwork. Currently, "this process burdens the medical profession, the employer, and the physically challenged."
- "Reevaluations need to be easier. They should just establish if anything has changed. It should be up to the doctor as to whether he feels more testing is warranted. I've had the battery of tests done three times now. My doctor said he is not running them again for insurance companies or government agencies."
- See also "Five Steps to Help Vestibular Patients Return to Work" (below), no. 3.

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### FIVE STEPS TO HELP VESTIBULAR PATIENTS RETURN TO WORK

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One VEDA member (a health professional) provided a list of five steps the SSA could take "to help vestibular patients return to work." VEDA felt that this response directed to the SSA is so relevant that it is worth quoting extensively:

1. *Provide a quick review process.* Get the vestibular-disabled person onto SSA disability and subsequent Medicare very quickly, because the condition can rapidly cause other problems, including injury from falls, hearing loss, confusion, deconditioning injuries, and depression. These secondary problems can be reduced when the disabled person has the financial assistance of SSA to seek help and even second opinions to find the best diagnosis and treatment possible for his/her disease. The most common story I hear from other vestibular patients is that most vestibular applications for SSA are denied the first time, and most patients have to go through a second evaluation to get benefits. This makes it too slow for the person who may be getting worse weekly. It took me about five years to find the correct diagnosis for my vestibular problem. For many patients, if they had SSA disability and Medicare assistance, they could have gotten a specialist's care sooner.

If they got assistance more quickly and found a treatment to control their symptoms faster, then their past job might still be available. The most success in returning to work would be to return to their past job if it does not require being in motion or watching motion (both are problems for me), because they

will not have to learn new skills if they remain vestibular-challenged. Learning something new is difficult for me, because my brain is already overloaded with confusing balance signals. It is like trying to learn something when you have not slept for several days or have the flu and your brain just does not want to stay alert. Vertigo and vestibular symptoms are not the same as having a mild “dizzy” spell, which many people experience.

2. *Accept on first review.* Accept the vestibular-disease patient who has documentation of a vestibular problem on the first review. I used to be able to tolerate stress very well, but since my vestibular problem started, stress makes me worse. Feeling you are in motion (or the world is) when you are not is already a big stress. Making many vestibular-challenged people go through a rejection and second review can decrease their energy and waste function that they otherwise could put on diagnosis, treatment, or future work. See how many patients were accepted on the first review last year and how many on second review and then make changes so that most patients are accepted on first review. By the time they are through two reviews, they would be more hesitant to “try” working while being treated for fear they might have to go through all that again.
3. *Reduce the amount of documentation needed for vestibular patients to get SS.* This is related to the patient going back to work later, because if they are so sick from all the work to collect documents, they won’t be able to do good rehabilitation for their vertigo. For example, I find it very difficult to fill in forms (the lines on the paper “wave”), copy papers (repetitive motions to put originals on/off the machine), write letters (I’m getting nauseated, weaker, and dizzy just writing this note), sort through papers and files (motion as you flip papers over), follow up with doctors on their reports, and organize (shuffle and move) things. All of these are required for applying for disability, and they need to be streamlined to get data to you [the SSA] using the least amount of forms and organizing by the vestibular person. I am often told, “Ask someone to help you”; however, family members are usually doing the multiple daily living items you can’t do, like food shopping, laundry (repetitive turning/bending), meeting with people (even a ten-minute conversation with someone who uses their hands to talk--and most do--is overwhelming), assisting you to doctors, even helping you walk down the hall or get into/out of the shower.
4. *Accept one significant, objective study for a patient as verification of vestibular problems.* Yes, the study should be objective and conclusive, but then do accept one. This is extremely important to helping the patient and getting them back to work faster. Let me say, as a patient, the vestibular studies are awful to go through. To me, it seems the tests are set up to make the vertigo worse, so it can be observed—and thus the problem is that the tests are designed to make the patient sicker. Two good examples are the caloric test, when cool water is put into the ear, which makes you feel like you are spinning; and the rotation chair test, when you are belted into a chair that is rotating. Most of the tests aren’t passive blood tests or x-rays; they require the patient or surroundings to move. Therefore, if you want the patient to use some remaining function to try to continue to work or go back to work, don’t torture them with a battery of tests when only one or two might objectively show that patient’s problem.

There are many vestibular tests, because the doctor is trying to find out if the problem is in the outer ear, middle ear, inner ear balance center, inner ear

hearing center, nerves to the brain, or the brain. Not all the studies are needed for every patient. And if the patient had all the studies to look for trouble in these six areas, then there might only be one study that shows the problem. Therefore, don't assume all studies that are conducted should be abnormal to show a problem. Only one objective, significant test is needed for some patients to confirm a vestibular problem and identify where the problem is located. Do not make any one test critical for disability. I have had some hearing loss, which was reversed with medication; however, the vestibular problem remains and is significantly more difficult for me to live with than the loss of hearing. Do not put hearing or other single tests as criteria. Ask in the guidelines to the doctors for copies of the significant tests showing disability, and not all the tests. This will help speed the process for medical records to get to you and will help your reviewers see the significant studies quickly.

5. *Include more neurological and vestibular tests in your list of possible studies.* For example, you have in Part III, Part A, Section 2.00 "positional and caloric testing, preferably by electronystagmography." Please list many more studies, including dynamic visual acuity, computerized dynamic posturography (CDP), ECOG, VEMP, VAT, and high-frequency pseudo-random rotational chair, plus others (ask neuro-otologists to recommend a list for you). Reduce requirement of image studies in the "blue book," as most vestibular problems from virus, congenital [causes], allergy, autoimmune, will not show up in imaging studies anyway. Eliminate reduced hearing as a criterion for vestibular disability, as these problems can occur separately. Don't ask for tests many patients don't need, such as "appropriate medically acceptable imaging reports of the skull and temporal bone." Most vestibular patients do not have a fractured skull or temporal bone, and the actual functioning of the inner ear does not show up on static images. Add more objective vestibular tests instead. However, make sure to keep the word "or" between tests, so that they do not all have to be completed on each patient if the physician does not need them. Extra tests beyond the ones the physician needs will make the patient sicker and less able to continue or return to work.

*The Vestibular Disorders Association is a 501 (c) 3 nonprofit organization dedicated to serving people with vestibular disorders by providing access to information, offering a support network, and elevating awareness of the challenges associated with these disorders.*

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