**Talking points for Awareness Day 2016 to Medical Providers**

* FND provides an umbrella term for a variety of genuine neurological symptoms such as paralysis, movement disorder, sensory symptoms and seizures, which are caused by abnormal nervous system functioning but not structural disease. The symptoms may be similar to or may co-exist with a wide range of other conditions such as migraine, MS and epilepsy. FND is often just as physically disabling.
* Functional disorders refer to bodily symptoms & disorders, which are genuine but not related to a defined disease process. The symptoms themselves exist at the interface between neurology and psychiatry. Finding positive features of FND on physical examination is of key importance in the diagnosis. A diagnosis should not be made by exclusion where as the physician cannot find an organic reason for the symptoms based on his few tests.
* Today over 7,000 rare diseases exist making it difficult for any specialist, let alone a primary care physician to diagnose. Many symptoms overlap making diagnosis difficult.
* According to NORD:
	+ The average patient spends five to seven years searching for a proper diagnosis.
	• They typically consult with up to eight physicians, receiving two to three misdiagnoses.
	• Physicians (both primary care and specialists) often don’t have the time, resources, or information to properly diagnose/manage patients with rare diseases, compared to more common diseases.
* Medically unexplained is not synonymous with medically unexplainable.
* Patient symptoms can be as debilitating as MS and Parkinson’s without the support. Despite these horrific symptoms many say isolation is the worst thing about this disorder. The shame, which accompanies the diagnosis, is due to the assumptions made from antiquated stereotypes.
* Patient care is compromised due to the lack of information made available at time of diagnosis in conjunction with the lack of knowledge and experience of the diagnosing physician
* The use of multiple terms: PNES, Conversion disorder, NEAD, Functional neurological disorder, psychosomatic, somatoform has only contributed to the confusion of this profoundly complicated area of medicine.
* Many have a rare disease yet to be diagnosed , others have not been tested for simple diagnosis such as B-12, adrenal failure, etc..
* Quality of care should not be based on the acceptance or understanding of the illness. at the end of the day it is unethical and dangerous to deny symptomatic treatment to patients who fail to fit medical stereotypes

**Tidbits from our Survey**

1. 61% of us do not believe psychological trauma, current or past, to be a cause of the illness. 25% aren’t sure, and 15% believe it is a cause.
2. What symptoms do we have (daily or frequently)?
	1. Pain – 82%
	2. Aches in muscles – 81%
	3. Aches in joints – 79%
	4. Cognitive/concentration problems (i.e. brain fog) – 79%
	5. Memory problems – 72%
	6. Muscle spasms – 70%
	7. Excessive sleepiness – 70%
	8. Numbness/neuropathy – 69%
	9. Gait disturbances – 67%
	10. Temperature regulation problems – 66%
	11. Speech problems – 64%
	12. Difficulty walking – requires use of cane, walker, scooter – 63%
	13. Noise sensitivity – 58%
	14. Insomnia – 58%
	15. Sensation of electrical shocks/pin pricks – 55%
	16. Muscle cramps 55%
	17. Tremor temporary – 54%
	18. Light sensitivity – 52%
	19. Digestive problems – 50%
	20. Touch sensitivity – 45%
	21. Getting stuck/frozen (temporary with sensation) 37%
	22. Seizures w/o loss of consciousness – 37%
	23. Tremor continuous – 36%
	24. Dystonia – 35%
	25. Paralysis – temporary (loss of movement and sensation) 32%
	26. Incontinence – 30%
	27. Myoclonus – 25%
3. Disability
	1. 56% have had to quit working or reduce hours to part time
	2. 42% have a significantly disrupted life
	3. 15% are on disability insurance
	4. 11% are not disabled
4. Childhood trauma – 70% of us don’t believe it is a factor, 19% are unsure, and 12% believe it is a factor