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**FACT SHEET**

**Neurological Movement Disorders**

**DYSTONIA**

**General Information (Dystonia)**

- ◆ Dystonia is a neurological movement disorder characterized by involuntary muscle contractions, which force certain parts of the body into abnormal, contorted, sometimes painful, movements or postures.<sup>1</sup>
- ◆ Dystonia is classified according to age of onset, bodily distribution of symptoms, and cause.
  - Age of onset can be during childhood (early onset) or during adulthood.
  - Dystonia can affect certain portions of the body (focal dystonia and multifocal dystonia) or the entire body (generalized dystonia).
  - Primary dystonia is when dystonia is the solitary symptom, unassociated with other pathology. Secondary dystonia is when the symptoms are the result of another health condition such as stroke or multiple sclerosis, or the result of injury such as trauma to the brain or lack of oxygen at birth.<sup>2</sup>
- ◆ Tardive dystonia, which is typically thought of as a type of secondary dystonia, is a form of the disease that occurs as a side effect of certain drugs.
- ◆ The causes of dystonia are unclear, except in the case of tardive dystonia.
- ◆ No known cure exists for dystonia.

**Key Statistics (Dystonia)**

- ◆ Dystonia affects about 250,000 people in the United States, making it the third most common movement disorder, following Essential Tremor and Parkinson’s disease.
- ◆ Dystonia affects more people than muscular dystrophy, Huntington’s disease, or Lou Gehrig’s disease.<sup>3</sup>

**Impact on Quality of Life (Dystonia)**

- ◆ Dystonia can seriously impair patients’ quality of life. The severe muscle contractions that characterize the disease can interfere with basic daily functions such as walking, sitting, sleeping, eating, and talking.
- ◆ Due to awkward postures and the inability to control certain muscles, some dystonia patients may find it embarrassing to go out in public.

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<sup>1</sup> Basic disease information taken from the Dystonia Medical Research Foundation, [www.dystonia-foundation.org/defined](http://www.dystonia-foundation.org/defined)

<sup>2</sup> Causes of dystonia discussion taken from “WE MOVE – Dystonia: Causes of Dystonia” [www.wemove.org/dys\\_cau.html](http://www.wemove.org/dys_cau.html)

<sup>3</sup> “What is Dystonia?” Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. [www.dystonia-parkinsons.org](http://www.dystonia-parkinsons.org).

- ◆ While dystonia can negatively impact patients' motor functions, the disease does not impair cognition, sometimes making patients feel like prisoners within their own bodies.
- ◆ Because dystonia can affect people who are still in childhood or in the prime of their lives, the disease can have an enormous impact on families and caregivers who must support severely disabled patients.

## **PARKINSON'S DISEASE**

### **General Information (Parkinson's disease)**

- ◆ Parkinson's disease is a complex, progressive and degenerative neurological disorder that causes loss of control over body movements.
- ◆ The primary motor symptoms of Parkinson's are:
  - Rigidity — stiffness or inflexibility of the limbs and joints
  - Bradykinesia/Akinesia — slowness of movement/absence of movement
  - Tremor — involuntary, regular, rhythmic shaking of a limb, the head, or the entire body
  - Postural Instability — impaired balance and coordination
- ◆ While tremor is the most recognized symptom of Parkinson's disease, it is rarely the most disabling symptom because the tremor generally occurs when the affected limb is at rest. Only five percent of Parkinson's patients cite tremor as the primary cause of their disability.

### **Key Statistics (Parkinson's disease)**

- ◆ Parkinson's disease is the second most common movement disorder and affects approximately 1 million people in the United States.
- ◆ The average age of onset for Parkinson's disease is 60. "Young-onset" Parkinson's disease may affect people between the ages of 20 and 40.
- ◆ Direct health-related expenses, indirect disability expenses and lost productivity in the United States amount to \$25 billion annually.<sup>4</sup>
- ◆ U.S. patients spend an average of \$1,000 to \$6,000 per year on Parkinson's medications alone.<sup>4</sup>

### **Impact on Quality of Life (Parkinson's disease)**

- ◆ As Parkinson's progresses, it becomes increasingly disabling, making routine daily activities like bathing, dressing or eating without assistance from others, difficult or impossible. Some patients with severe Parkinson's disease become wheelchair-bound or bedridden.

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<sup>4</sup> Michael J. Fox Foundation and the Parkinson's Action Network

- ◆ Patients can experience extreme swings in movement control — from periods of virtually normal motor function, to episodes of complete immobility — in the span of a few hours.
- ◆ The disabling effects of Parkinson’s disease and the unpredictable onset of side effects from treatment with the drug levodopa may cause many patients to become unwilling or unable to venture outside their homes to work, shop, eat or socialize — everyday activities that most people take for granted.
- ◆ The inability of some advanced Parkinson’s patients to care for themselves can lead to a loss of dignity and self-esteem, and also impacts caregivers.

## **ESSENTIAL TREMOR**

### **General Information (Essential Tremor)**

- ◆ Tremor is a rhythmic, shaking movement of part of the body produced by involuntary muscle contraction and relaxation. It often occurs in the limbs, head, or voice.
- ◆ Tremor is the only symptom of Essential Tremor, the most common neurological movement disorder.
- ◆ Essential Tremor usually affects both sides of the body and is made worse by stress or anxiety. Patients usually experience “action tremor,” which occurs when a limb is in use, or “postural tremor,” which occurs when a limb is outstretched.

### **Key Statistics (Essential Tremor)**

- ◆ Approximately 1.5 million people in the U.S. are afflicted with Essential Tremor, the most common movement disorder.
- ◆ Essential Tremor is a progressive disease and tends to run in families. Approximately 30 percent of Essential Tremor patients have an immediate family member with the condition.
- ◆ The disorder can afflict persons of any age or gender; the average age of onset is 45.

### **Impact on Quality of Life (Essential Tremor)**

- ◆ Tremor often becomes increasingly disabling, prohibiting patients from performing routine daily activities. Even simple activities such as writing checks legibly, raising a fork to eat, or holding a glass of water without spilling, are difficult for people with tremor.
- ◆ As the disease progresses and the tremors become more disabling, patients may withdraw from social situations because of discomfort and embarrassment.