

Understanding Multiple Sclerosis

National Multiple Sclerosis Society
Pacific South Coast Chapter
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Society Overview

- Founded in 1946. Pacific South Coast Chapter includes San Diego, Orange and Imperial Counties.
- Our goal: to help those living with multiple sclerosis lead healthier, happier lives.
- A resource for clients, families, and health care providers.

What is MS?

- Multiple sclerosis is a chronic disease of the central nervous system (CNS) that interferes with the brain's ability to send and receive messages.
- MS is thought to be an autoimmune disease.
- Nerves in the brain and spinal cord are covered with a fatty, protective covering called myelin. Myelin functions like an insulating cover on an electric wire, sending electrical impulses to and from the brain.

What is MS?

- The body's own defense system attacks the myelin.
- Damaged myelin may form scar tissue (sclerosis).
- Sometimes the nerve fibers are severed.

Who Gets MS?

- In the U.S. It is estimated that there are about 400,000 people with MS.
- MS is more common in women than men.
- MS is most frequently diagnosed between the ages of 20-50.
- MS is less common in equatorial climates than in cold climates.
- MS is neither contagious nor fatal.

Common Symptoms

- Fatigue
- Weakness

- Numbness and tingling
- Stiffness (spasticity)
- Tremors
- Difficulty walking
- Visual problems
- Speech problems

How is MS Diagnosed?

- There is no definitive diagnostic test for MS.
- The nature of MS makes diagnosis difficult. Symptoms often come and go.
- A physician, usually a neurologist, makes a diagnosis based on the description of symptoms along with findings from the neurological exam and MRI's.

What Causes MS?

- The exact cause of MS is still unknown.
- It is believed that both environmental and hereditary factors are involved in the development of MS, however; these specific factors have not yet been identified.

Types of MS

- Relapsing-remitting – periods where symptoms come and go.
- Primary-progressive – no clear exacerbations and remissions, just slow worsening of symptoms.
- Secondary-progressive – begins as RR, but with incomplete recovery after each exacerbation.
- Progressive-relapsing – continued deterioration from the time of diagnosis, with relapses.

Relapsing-Remitting MS

How is MS Managed?

- Maintaining good health habits
- Physical therapy
- Occupational therapy
- Speech therapy
- Counseling
- Medication

Treatments to Slow the Progression of MS

While there is currently no cure, there are seven different treatments options for people with MS:

- Avonex (Interferon beta 1a)

- Betaseron (Interferon beta 1b)
- Copaxone (Glatiramer acetate)
- Extavia (Interferon beta 1b)
- Novantrone (Mitoxantrone)
- Rebif (Interferon beta 1a)
- Tysabri (Natalizumab)

2009 Community Survey

General

- Nearly 25% living near poverty levels
- Nearly 70% dealing with physical disability or walking limitations

Insurance

- Nearly 15% declined insurance because of their MS diagnosis
- Private insurance 69.4%, Medicare 32.5%, MediCal 11.9%

Family Support

- 75% living with family, 18.5% living alone
- 64.6% concerned about relying on family or friends for help in the future

Housing

- 60.4% concerned about being able to live independently in own home
- Nearly 24% needed help with home modifications in the past year

Financial Challenges

- Annual cost of MS for the year 2007 \$70,000/person
- Only 20-30% of people with MS are still in the workforce after 15 years
- Disease modifying drugs can cost \$3000/month

Our Programs

- Financial Assistance Program
- Financial Planning Program
- Durable Medical Equipment (DME)
- Chore Service, transportation

Advocacy Policy Priorities—Federal

- Increased MS research
 - Congressionally Directed Medical Research Programs (CDMRP)
 - National Multiple Sclerosis Disease Registry
- Health care reform
 - Health care reform principles
 - Affordable Access to Prescription Medications Act of 2009
- Disability rights
 - Access to quality health care
 - Long-term care resources
 - Lifespan Respite Care
- Accessible, affordable insurance
 - Eliminate the 24-month Medicare Disability Waiting Period

- Congressional Multiple Sclerosis Caucus

Advocacy Policy Priorities—State

- Ensure that drug manufacturers are held accountable to MS-CAN sponsored bill (SB 486) on safe needle disposal.
- Sponsor legislation to provide greater disclosure of the drug pricing system and to address out of pocket prescription costs.
- Initiate legislation that would require insurers to provide coverage for Durable Medical Equipment (DME).

Client Programs and Services

- Education and Information
- Information for those newly diagnosed, referrals and seminars
- Emotional Support Services
- Support groups, counseling and professionally-led groups
- Wellness Programs
- Aquatics, yoga, strength training and more
- Family Support Programs
- Relationship Matters, family fun days, caregiver programs, family respite care, Angel Visitation

JOIN THE MOVEMENT

- How can you help the National MS Society support people with MS?
- Referral list
- Advocate
- Volunteer
- Donate

CONTACT US

1-800- 344-4867

www.mspacific.org

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