

Spinal Muscular Atrophy (SMA)

Spinal Muscular Atrophy (SMA) is a genetic motor neuron disease affecting one in every 6,000 babies. It is a group of inherited diseases that damages the nerves controlling voluntary muscle movement which affects crawling, walking, head and neck control. Cognition and intellect, emotional development and sensory nerves are typically unaffected. SMA can strike anyone of any age, race or gender. For a child to have SMA, both parents must be carriers of the genes. If both parents are carriers, there is a 25% chance their child will have SMA. One in every 40 people carry the gene. There are basically four different forms of the disease varying in severity and age at onset.

Our goal is to work with you and your child to provide the best quality of care and life possible. Due to possible complications of the condition, your physician may recommend that you see a few medical specialists including:

- Pulmonologist - for lung and respiratory (breathing) issues
- Orthopedist – for issues related to bones and the associated muscles, ligaments and other soft tissue
- Occupational Therapist – to improve feeding and activities of daily living
- Physical Therapist – to improve mobility and coordination
- Nutritionist – for nutritional counseling because diet can affect the symptoms of SMA

Information and Support

We understand that this is a difficult time for you and your family. Please know that you are not alone. There are wonderful, supportive families and resources in the Western New York area who are willing to help you through this experience.

One of the best local resources for SMA is the **Families of Spinal Muscular Atrophy – Western New York Chapter**. Their website is: www.wnyfsma.org and their phone number is: (716) 622-0804 – Bonnie (President).

We encourage you to contact them.

A list of other important phone numbers and informational resources can be found on the other side of this sheet.

If you have any questions, please do not hesitate to call us: (716) 878-7840.

Important Phone Numbers

Emergency Room – ask for Neurologist on Call	878-7408
Department of Neurology	878-7840
Pulmonology	878-7524
Orthopedics	878-7171
Physical & Occupational Therapy (Robert Warner Clinic)	878-1260
Nutritionist	878-7425
Pediatrician	_____
Facilitated Enroller	
Social Worker	
School	Teacher/Counselor
Bus	

Information & Support

Families of Spinal Muscular Atrophy – Western New York Chapter www.wnyfsma.org
Local chapter dedicated to helping families with SMA. (716) 622-0804 – Bonnie (President)

Families of Spinal Muscular Atrophy www.curesma.org
Largest international organization dedicated to helping & educating families & professionals about SMA.

E-mail forum for Families of Spinal Muscular Atrophy www.fsma.org/bbsma/
Dedicated to several topics about SMA.

Spinal Muscular Atrophy Foundation www.smafoundation.org
The mission of the Spinal Muscular Atrophy Foundation is to accelerate the development of a treatment or a cure for SMA. (646) 253-7100

The Independence Foundation www.TheIndependenceFoundation.org
Local organization helping individuals with disabilities live independent and self directed lives. (716) 685-3976 – Chris

Muscular Dystrophy Association (MDA) www.mda.org
MDA is a national voluntary health agency dedicated to conquering more than 40 neuromuscular diseases that affect a million Americans of all ages. Buffalo office: (716) 626-0035

Fight Spinal Muscular Atrophy (SMA) www.fightsma.org
Fight SMA is an international nonprofit organization dedicated to finding a treatment or cure for spinal muscular atrophy (SMA).

United Way of Buffalo & Erie County (716) 887-2626 www.uwbec.org

Department of Social Services (716) 858-8000 www.erie.gov/depts/socialservices