

# 2009 ANNUAL APPEAL

[www.curesma.org](http://www.curesma.org)

## Families of SMA Leading the Way for a Treatment and Cure for SMA

### Research

Families of SMA remains committed to supporting innovative ideas that will lead to a treatment and cure for SMA. We support research from basic ideas to clinical trials and have a history of working with partners to advance our vision of a world without SMA.

Your support continues to be critical as we move toward a treatment and cure, but we can not stop supporting creative solutions. Families of SMA's cutting edge programs are showing promise, but there is a long way to go before this terrible disease is cured.

For the latest update on Families of SMA's Research programs, visit our website at [www.curesma.org](http://www.curesma.org)

### Family Support and Patient Services

Families of SMA services and support programs assist patients and families affected by SMA at all stages of the disease: from first diagnosis; to managing the disease; to improving daily life with SMA.

Families of SMA is committed to making a difference in the lives of all the families we serve both today and tomorrow.

### Families of SMA Programs are Making a Difference in the Lives of SMA Families Across the Country

- Newly Diagnosed Families receive critical items such as Care Packages; Sheep Skin Blankets; Radio Flyer Wagons; Dinners; and Home Support
- Families of SMA Equipment Pool
- Medical Care including the "Ask the Expert" Service
- Daily Living Support and Advise
- Local Support – Connecting you to a local SMA family

### The Annual SMA Conference - Including the FSMA Newly Diagnosed Conference Program

This one –of-a-kind conference where families and researchers come together to explore, learn and share all that is SMA. Last year more than 225 Researchers and 400 families attended the conference. This year the conference is scheduled at the end of June in Santa Clara California – Visit our website at [www.curesma.org](http://www.curesma.org) for details!

### Dear Friends,

This year the Board of Directors took the opportunity to look to the future and see what opportunities and challenges lay ahead. Now with an updated mission, Families of SMA has a clear map for the future and how to enhance both the research and support programs that we provide to our community.

We continue to move forward aggressively to implement new programs including those to assist newly diagnosed families. We are improving and adding to our patient services and family support programs, launching the new Medical Advisory Council, and producing new publications available at no charge to families and medical professionals on several SMA topics.

Families of SMA is here today because of the strength of all our families! We know we are making significant strides in developing a treatment and a cure for SMA, and we have accomplished this by working and supporting each other. Thank you for all your hard work and continued support of FSMA!

Sincerely,  
Paula Barrett  
*Chair, Board of Directors*

**Families of SMA now provides services and support to 70% of all newly diagnosed families**



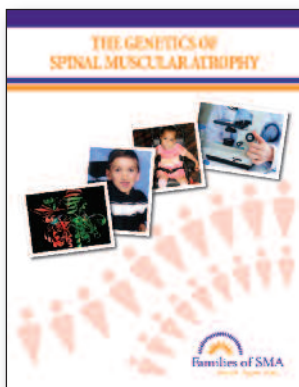
# Check Out All the New Families of SMA Publications



## Family Guide to Research

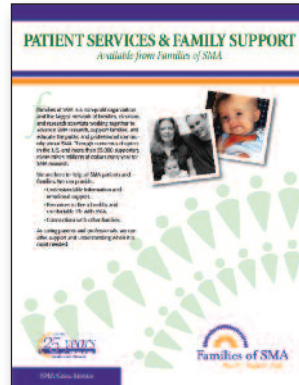
This guide helps to answer questions such as what are the key areas of SMA research and what are the costs for conducting SMA drug development and clinical trials. Clear definitions and graphics are included to help explain and illustrate how SMA drugs begin and the key steps involved in developing new therapies for Spinal Muscular Atrophy. The topics in this new booklet cover the following important areas of SMA research:

- SMA Researchers.
- Drug Research.
- Gene Therapy.
- Stem Cells.
- Clinical Trials.
- Government Research and The FDA.



## The Genetics of Spinal Muscular Atrophy

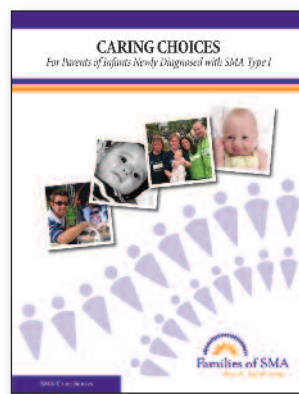
Confused about genes, proteins, DNA, and how SMA is diagnosed? Read this helpful pamphlet. It includes definitions, explanations, and diagrams from genetics expert, Louise Simard, Ph.D. and the FSMA Medical Advisory Council.



## Patient Services & Family Support

This booklet has details on the following Families of SMA programs:

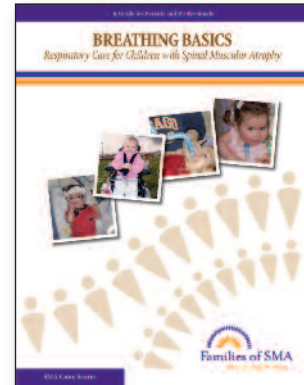
- Newly Diagnosed Conference Programs
- Families of SMA Equipment Pool.
- “Ask the Expert” Service and Medical Care.
- Daily Living and Local Support.
- How to Keep Up to Date.
- The Annual SMA Conference.



## Caring Choices

This booklet is focused on caring choices for parents of infants newly diagnosed with Spinal Muscular Atrophy Type I. The topics review the basics of the main care options for newly diagnosed SMA Type I:

- What is Non-Invasive Respiratory Care.
- What is Invasive Respiratory Care.
- What is Palliative Care.
- Where you can go for support and guidance.



## Breathing Basics

This new booklet is focused on the critical aspects of respiratory care for children with Spinal Muscular Atrophy. The booklet was authored by Mary Schroth, M.D., a member of the Families of SMA Medical Advisory Council, and a leading expert on respiratory care for SMA patients. This booklet reviews the following important topics:

- Why is respiratory care so important in SMA.
- What are common respiratory problems in children with SMA.
- Elements of respiratory care management in SMA:
- What are special needs of children with SMA Type I.
- What are special needs of children with SMA Type II.
- What are special needs of children with SMA Type III.
- What respiratory equipment will you need at home.

If you would like a hard copy mailed to you please email us at [info@fsma.org](mailto:info@fsma.org) or call (800) 886-1762.