

# PATIENT SERVICES & FAMILY SUPPORT

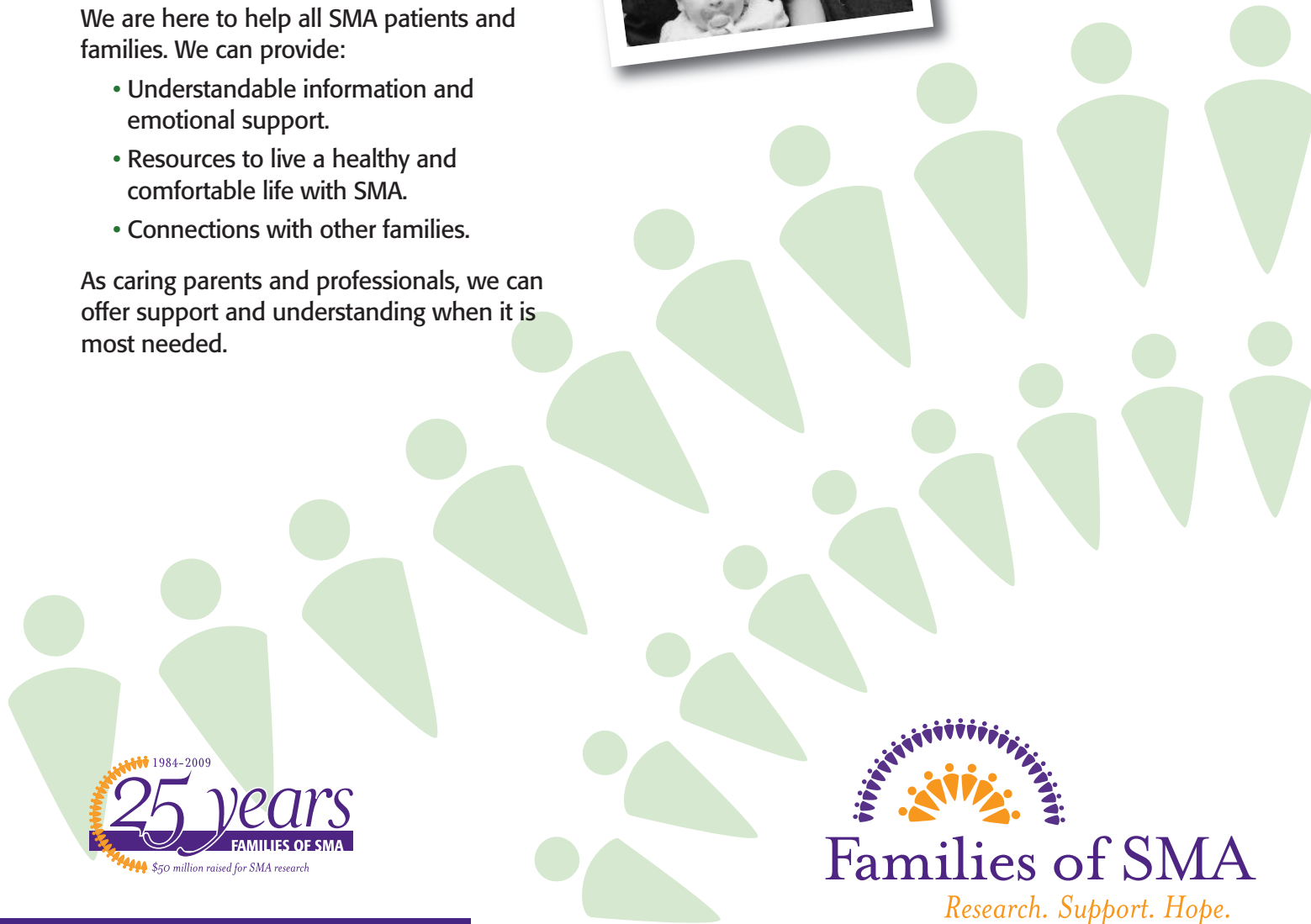
*Available from Families of SMA*

*f*amilies of SMA is a non-profit organization and the largest network of families, clinicians, and research scientists working together to advance SMA research, support families, and educate the public and professional community about SMA. Through numerous chapters in the U.S. and more than 55,000 supporters, FSMA raises millions of dollars every year for SMA research.

We are here to help all SMA patients and families. We can provide:

- Understandable information and emotional support.
- Resources to live a healthy and comfortable life with SMA.
- Connections with other families.

As caring parents and professionals, we can offer support and understanding when it is most needed.



## For Newly Diagnosed Families

If you are a family recently diagnosed with SMA, please e-mail [infopack@fsma.org](mailto:infopack@fsma.org) or call the FSMA office at (800) 886-1762.

We are available for emotional support and will express mail a comprehensive new diagnosis information packet to you. Families of SMA has a number of networking programs available that link families together for mutual support.

### Special Type I Programs

These programs have been designed by Type I families to assist other Type I families.

#### Care Packages

Created and put together by SMA parents Mary Jane and Tim Utzat, with SMA Type I appropriate toys, blankets, swings and other items that help stimulate SMA infants.

#### Sheep Skin Blankets

Through the CAM Fund, the sheep skin blankets help with tissue break down and give the babies extra comfort and the ability to sleep better without having to be turned as often.

#### Radio Flyer Wagons

Through the Tumbleweed Wagon Fund, the wagons are beneficial for transporting babies once they lose muscle tone and must remain horizontal around the house, yard, doctors' offices, hospitals, stores, etc.

#### Dinners

Through the Rappoport Foundation, have dinner delivered to your home, so that for even one day you have one less thing to think about and can spend a few extra minutes reading a story, singing songs or giving your baby some extra kisses.

#### Home Support

Through the Angel Baby Foundation, have groceries delivered, home cleaning, other services, and special gift boxes.

#### Respiratory DVD

Provided by SMA parent Dana Craven.



## Equipment Pool

Families of SMA has a collection of equipment suitable for SMA children, including car beds, bath chairs and strollers. The items are specifically focused on the critical emergency equipment and supplies that you may need. This service is available free of charge to all members of Families of SMA.

Call the FSMA office at (800) 886-1762 or e-mail [equipment@fsma.org](mailto:equipment@fsma.org) for more information.

## Medical Care

Families of SMA has comprehensive information available on critical topics in SMA medical care including:

- Genetics
- Respiratory Care
- Physical and Occupational Therapy
- Orthopedics
- Nutrition
- Palliative Care

We have a number of booklets available at no cost to you, and a special medical issues section of the FSMA website, covering these topics.

### Ask the Expert Service

Get answers to important care and health-related questions with the help of FSMA Medical Advisory Council experts. Our free online Ask the Expert feature connects you with leading SMA physicians and clinicians.

## Daily Living

Families of SMA can provide advice and information on many topics including:

- Education for SMA affected individuals.
- Information specifically for adults with SMA.
- Relationships.
- Parenting issues including coping with the diagnosis, adapting toys for SMA children and many articles written by parents of SMA children.
- Traveling.
- Community forums.

Visit the Daily Life section of the Families of SMA website for more information.

# The Annual SMA Conference



## Local Support is Available

Families of SMA has chapters throughout the US with dedicated family volunteers. These committed and experienced individuals are available to provide support and advice on a local level in your community.

Visit our website at:

[www.curesma.org/fsmacommunity/chapters/](http://www.curesma.org/fsmacommunity/chapters/)  
or call (800) 886-1762 to get connected with your local chapter.

## Keep Up to Date

Sign up as a member of FSMA and receive regular mailings:

- Quarterly newsletter "Directions" with community news, medical progress and advice, information on daily living, letters from families, upcoming events and other resources.
- Quarterly newsletter "Compass" with the latest news on SMA research developments.



Also, sign up for our elist and receive monthly emails with all the latest news from the SMA community.



Since 1988, Families of SMA has hosted an annual conference so that families can hear about the latest research, gain an understanding of the disease, share the latest in disease management techniques and therapies, and network with other families and professionals. Close to 1,000 families, patients, researchers and medical professionals gather together on an annual basis.



For the last 13 years this conference has been held in conjunction with the annual International SMA Research Group Meeting. This gives the opportunity for families to actually meet the researchers who are looking for a treatment and cure for SMA, as well as with some of the most outstanding doctors and clinicians in the field of SMA.

This is the largest conference in the world for those affected by SMA, and also for those involved in providing support and care for SMA patients. There is no other program like this for those affected by SMA in the world. The aspect of interactions between the researchers and families at one conference is extremely special. The annual conference also provides our children an opportunity to make new friends and have a great time.

Financial need scholarships are also available to assist SMA families attend the conference.

## Newly Diagnosed Conference Program

**FSMA will cover the registration fees for the SMA Conference for all families newly diagnosed since the last meeting.** Our goal is to allow as many newly diagnosed SMA families as possible to attend and experience the benefits of this amazing conference. The meeting gives families the opportunity to gather critical care and daily living information early after diagnosis, learn directly from experienced SMA physicians, and network with other families.

This program is automatically offered to all newly diagnosed families that contact FSMA.





## **Families of Spinal Muscular Atrophy is dedicated to creating a treatment and cure by:**

- Funding and advancing a comprehensive research program;
- Supporting SMA families through networking, information and services;
- Improving care for all SMA patients;
- Educating health professionals and the public about SMA;
- Enlisting government support for SMA; and
- ***Embracing all touched by SMA in a caring community.***

Our vision is a world where Spinal Muscular Atrophy is treatable and curable.

## **National Office**

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### **Families of Spinal Muscular Atrophy**

P.O. Box 196, Libertyville, IL 60048-0196

Phone: (800) 886-1762

Fax: (847) 367-7623

Email inquiries: [info@fsma.org](mailto:info@fsma.org)

Families of SMA on the Web: [www.curesma.org](http://www.curesma.org)

## **Additional Free Booklets from Families of SMA**

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- Caring Choices: For Parents of Infants Newly Diagnosed with SMA
- Breathing Basics: Respiratory Care for Children with Spinal Muscular Atrophy
- The Genetics of SMA
- Understanding Spinal Muscular Atrophy
- Family Guide to the Consensus Statement for Standard of Care in SMA