



# Cure SMA Family Support and Patient Services

Cure 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 110,000 members & supporters, Cure SMA 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.

If you know someone that has been recently diagnosed, please call us at 800.886.1762 or email [infopack@curesma.org](mailto:infopack@curesma.org)



**Make today a breakthrough.**

# Welcome to the Cure SMA Community

The diagnosis of spinal muscular atrophy can be confusing, scary, frustrating, pretty much the whole gamut of emotions... but you are not alone. You are now part of Cure SMA, a network of families, researchers, clinicians and other professionals who are determined to make a difference.



Cure SMA is a non-profit organization and the largest worldwide network of families, clinicians and research scientists working together to support families, educate the public and professional communities about SMA, and advance SMA research.

Cure SMA is a resource for unbiased support. We are here to help all individuals living with SMA and their loved ones, and do not advocate any specific choices or decisions. Parents and families make different choices regarding what is best for their families and children, consistent with their personal beliefs. Parents and other important family members should be able to discuss their feelings about these topics, and ask questions to their SMA care team. Such decisions should not be made lightly and all options should be considered and weighed carefully. All choices related to SMA are highly personal and should reflect personal values, as well as what is best for each child, individual, and family. Families are never alone. Cure SMA is always just a phone call or email away.



As caring parents and professionals, we can offer support and understanding when it is most needed. Through phone and multimedia networking, the team at Cure SMA is here to support you, along with other families and friends affected by SMA. We provide invaluable support and services to individuals and families such as medical information and equipment, family support and resources, an annual conference, local community support through our vast volunteer network, regular publications and web-based support.

Cure SMA is here for you at whatever level you need. We hope to provide you with a variety of information that will help you navigate through life with SMA. We are here to help connect you with other families and to provide resources to assist in the care of a family member with SMA. Together, we are all here working to fund the research that will lead us to a treatment and a cure for SMA.

Do not hesitate to email or call us at anytime at [familysupport@curesma.org](mailto:familysupport@curesma.org) or 800.886.1762..

**If you are a family recently diagnosed with SMA, please e-mail [infopack@curesma.org](mailto:infopack@curesma.org) or call the Cure SMA national office at 800.886.1762. We are available to support you and will overnight a comprehensive newly diagnosed informational packet on SMA to you. We will also send a Newly Diagnosed Care Package of toys for your child and a binder full of resources that is specific to your state. These Newly Diagnosed Care Packages are made possible through donations and ideas from other SMA parents.**

# For Newly Diagnosed Families

If you are a family recently diagnosed with SMA, please e-mail [infopack@curesma.org](mailto:infopack@curesma.org) or call the Cure SMA national office at 800.886.1762. We are available for emotional support and will overnight a comprehensive newly diagnosed informational packet on SMA to you. We will also send a Newly Diagnosed Care Package of toys for your child and a binder full of resources that is specific to your state. These Newly Diagnosed Care Packages are made possible through donations and ideas from other SMA parents.

Cure SMA has a number of networking programs available that link families together for mutual support. If you are interested in networking, please let us know and we would be happy to connect you. For local support, most states have a Cure SMA Chapter, made up of SMA parents, relatives and friends, where you can connect with local families and attend many events going on in your state. Chapters are also a good way to find out about local resources.

The Annual SMA Conference is a wonderful opportunity to connect and meet other SMA families. This conference is the largest conference in the world for people affected by SMA. Families come from all over to attend the workshops and receive the most up-to-date information on SMA.

We send SMA type I, type II, and type III care packages to all newly diagnosed families who contact Cure SMA. Each care package is specific to the type of SMA that the child has. These care packages include a range of items such as informational materials, toys appropriate for individuals with each type of SMA, books, blankets, hand-made quilts, and DVD's. Many ideas for the items in these Care Packages come from SMA parents themselves.



NEWLY DIAGNOSED

## SMA TYPE I PROGRAMS

### Care Packages

The Cure SMA Care Packages are sent to every newly diagnosed SMA family who contacts Cure SMA. The Cure SMA Newly Diagnosed type I Care Packages were originally created by Donna and Alex Abraldes, in 2001, in memory of their daughter, Deirdre. In 2007, Mary Jane and Tim Utzat began purchasing items and making these care packages out of their home, then shipping them to the Cure SMA national office to send to newly diagnosed type I families. The type I Care Packages are now funded by the *Jacob Isaac Rappoport Foundation* in memory of their "Shooting Star," Jacob, who had SMA type I. Shaina and Adi Rappoport created their foundation in the hopes of reaching out and helping other families affected by SMA. Through their generous funding, we have been able to send over 200 type I Care Packages each year to newly diagnosed type I families.



Many ideas for the items in the type I Care Packages come from SMA parents themselves. Items are often donated for the care packages in honor or in memory of a child with SMA. Some of the items in the Newly Diagnosed type I Care Packages include:

- **Sheepskin Blanket** - The sheepskin blankets have been found to help with preventing tissue breakdown and to reduce the need for turning children that cannot turn themselves.
- **Infant Bath Pad** - A great way to support your child in or out of the tub at just a slight incline.
- **Links** - Links are great to link things low enough to tug on. Can be used to attach various toys to swings, car seats, etc. They can be used as teething rings, as regular teething rings may be too heavy.
- **O-Ball** - A ball full of finger holes that is easy to hold and play with.
- **Handmade Quilts**
- **Baby Print Hand Mold Tins** - A nice keepsake activity to do with your child.

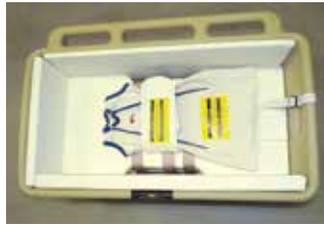


We also try to include very lightweight items so that a child with SMA can hold them. Here are a few items that are included:

- **Lightweight Spoons**
- **Cat Toys**
- **Finger Puppets**
- **Balloon on a Stick**
- **Feathers**

## Car Beds

Cure SMA is thrilled to receive generous funding from Sweet Baby Zane and Hillary & Keith Schmid to purchase car beds for the Cure SMA Equipment Pool. These car beds are vital to the well being of SMA type I infants, who may experience possible apnea and oxygen desaturation if they are placed in a regular infant car seat. These car beds enable an infant with special needs to be positioned in the prone or laying down position, safely and comfortably in the car. After their precious daughter, Zane, passed away, Hillary and Keith were determined to bring awareness to SMA. Along with their supportive community, Hillary and Keith formed *Sweet Baby Zane* and organized fundraisers in Zane's memory. They have provided enough funding for Cure SMA to purchase Hope Car Beds and Cosco Dream Ride Infant Car Beds. If you are interested in receiving a car bed for your child, please contact the Cure SMA office at 800.886.1762 or email [equipment@curesma.org](mailto:equipment@curesma.org).



## Wagons

Cure SMA receives generous funding from donors to provide wagons for our Newly Diagnosed Care Package Program. We are thrilled to be able to provide wagons to all newly diagnosed families once they contact Cure SMA and request one. These wagons are beneficial for all types of SMA.

For infants with type I, the wagons are wonderful, as they often are required to lay flat once the babies lose muscle tone and cannot adequately support themselves. The wagons are incredibly beneficial for transporting them around the house, yard, neighborhood, doctor's office, hospitals, etc. Parents love having these wagons as an easy way to move their child from one location to another, as opposed to being picked up and carried frequently for feedings or diaper changes. Additionally, attachments can be added to the wagon to hang their favorite toys, tie balloons, or hang bolus or enteral feeding bags. We recommend lining the wagon with egg-crate foam, memory foam, or a sheepskin blanket, which is provided in our Newly Diagnosed Care Packages, for comfort. Cure SMA is happy to provide this wagon to our

families which is comfortable and enjoyable for the child and in some small way, makes the challenge of dealing with spinal muscular atrophy more manageable for parents and caregivers. For more information about how to receive a wagon, please contact the Cure SMA office at 800.866.1762 or email us at [familysupport@curesma.org](mailto:familysupport@curesma.org).



## NEWLY DIAGNOSED

### Newly Diagnosed Binders

The Newly Diagnosed Binder is a program that was recently launched as a way to help families with information and resources specific to each state. These binders contain important information about SMA, including all of the SMA Care Series Booklets and a list of resources available to the family in their own state. This binder also acts as an organizational tool, where families can keep important medical information concerning their child, all in one location.

### SMA TYPE II AND SMA TYPE III PROGRAMS

#### Care Packages

Cure SMA began a new care package program on January 1st, 2010, for newly diagnosed type II and type III families. These care packages are made up of many items that have been suggested by other SMA families and are sent out to newly diagnosed type II or type III families who contacts Cure SMA.

#### Some Of The Items In The Newly Diagnosed SMA Type II Care Packages Include:

- **Crayola Twistable Slick Stix** - These twistable crayons are super smooth and glide easily across the page for children with SMA.
- **Book “Smasheroo”** - A children’s book written about siblings with SMA type II and type III.
- **Sheepskin Blanket** - The sheepskin blankets have been found to help with preventing tissue breakdown and to reduce the need for turning children that cannot turn themselves.
- **Play-Doh** - A fun activity that allows SMA kids to work on their fine motor skills while playing!
- **O-Ball** - A ball full of finger holes that is easy to hold and play with.
- **Handmade Quilt**





### Some Of The Items In The Newly Diagnosed SMA Type III Care Packages Include:

- **Crayola Twistable Slick Stix** - These twistable crayons are super smooth and glide easily across the page for children with SMA.
- **Book “Smasheroo”** - A children’s book written about siblings with SMA type II and type III.
- **Play-Doh** - A fun activity that allows SMA kids to work on their fine motor skills while playing!
- **Large Knob Wood Puzzle** - These puzzle pieces have knobs on each piece which makes them easier to grab for children with SMA.
- **Handmade Quilt**

### Wagons

Cure SMA receives generous funding from donors to provide wagons for our Newly Diagnosed Care Package Program. We are thrilled to be able to provide wagons to all newly diagnosed families once they contact Cure SMA and request one. These wagons are beneficial for all types of SMA. For type II and type III families, these wagons are ideal for parents to be able to transport their children without the use of a stroller or wheelchair.

### Newly Diagnosed Binders

These binders contain important information about SMA, including all of the *SMA Care Series* booklets and a list of resources available to the family in their own state. This binder also acts as an organizational tool, where families can keep important medical information concerning their child, all in one location. Every family receives a binder in their Newly Diagnosed Care Package.

# SMA Information – Keep Up to Date

Cure SMA has comprehensive information available on critical topics in SMA medical care including genetics, respiratory care, nutrition and so much more. We have a number of booklets available at no cost to you, and a special medical issues section of the Cure SMA web site, covering these topics.

We also provide our members with a subscription to our Family Support Newsletter called *Directions*, and our publication dedicated to SMA research news and progress, called *Compass*. *Directions* contains information on daily living, letters and stories from families, upcoming events, articles by doctors and researchers, and other resources. *Compass*, which is published several times a year, is a Cure SMA newsletter focused on research updates, highlighting all of the major research developments.

Cure SMA offers free informational booklets called *SMA Care Series* to all families, friends and professionals. These booklets are available on a variety of specific topics such as genetics and diagnosis, respiratory care, nutrition and many more. *SMA Care Series* booklets are also now available in Spanish, as well as on our website for download.

Sign up for our e-list and receive monthly emails, with the most up-to-date information and events happening within the SMA community, by emailing [membership@curesma.org](mailto:membership@curesma.org).



**Cure SMA is proud to offer all of the SMA Care Series booklets translated in Spanish.**



## THE CURE SMA WEBSITE - [WWW.CURESMA.ORG](http://WWW.CURESMA.ORG)

The Cure SMA website provides vital up-to-date information and advice that families need on a variety of SMA-related issues. The website is here to help guide families through a wide variety of general information on SMA. Some of the information available includes:

- Coping with the SMA diagnosis
- Advice and information on the basics of SMA, where we have links to our SMA Care Series Booklets in PDF format, quick facts on SMA and frequently asked questions
- Education for SMA-affected individuals
- Cure SMA Publications
- Information on SMA medical care including respiratory care, physical and occupational therapy, and nutrition
- Adapting toys for SMA children
- Information on the Annual SMA Conferences
- Links to Cure SMA chapter pages
- Resources for grief and loss
- Information for adults with SMA
- Legislative Information

Visit [www.cureSMA.org](http://www.cureSMA.org)

## INFORMATION PROVIDED WORLDWIDE

For our international members and friends, Cure SMA has created a wonderful opportunity to share the latest SMA information with everyone around the world. Thanks to funding from Sweet Baby Zane, any international family or professional who contacts Cure SMA, is able to receive a CD with all of the SMA Care Series Booklets and newsletters, in a PDF format. There is also a feature that allows any family to be able to translate the information to the language of their choice.

## INFORMATION FOR MEDICAL PROVIDERS

Cure SMA will provide a primary care provider packet to any primary care provider who contacts Cure SMA or through a family submission. These packets are specifically designed for primary care providers who may not be familiar with Spinal Muscular Atrophy. We hope to encourage and spread SMA awareness throughout the medical community by sending this important information to providers. If you would like your medical providers to receive a Primary Care Provider Packet, please email [info@curesma.org](mailto:info@curesma.org) or call 800.886.1762.



## CARE PROVIDER MAILING LIST

The Cure SMA care provider mailing list is a database containing our professional members. The database includes: pediatricians, neurologists, pulmonologists and many other medical professionals. We keep these providers up to date on the latest SMA information available, by mailing them all new and updated *SMA Care Series* Booklets. Our care provider mailing list currently includes over 1,000 providers from all over the US. If you would like any of your family's care providers added to this mailing list, please email [info@curesma.org](mailto:info@curesma.org) or call 800.886.1762.



## SMA SOCIAL NETWORKING

**The Cure SMA Facebook page** is the best place to receive constant updates on anything and everything SMA related. These updates may include: research announcements, new care package items, equipment pool items, fundraising and local events, chapter updates, interest stories, Annual SMA Conference information and updates and much more. It is also a wonderful place to network with many SMA families worldwide.

# Equipment Pool

Cure SMA understands the financial hardship of living with SMA, and the organization maintains an equipment pool, which is available free of charge to members of Cure SMA. The equipment pool includes a widespread list of equipment suitable for children with SMA. Once the family is no longer in need of the item, we kindly ask them to return their equipment back to Cure SMA, so that we are able to loan it to another family. Some of the items in our equipment pool have been donated by other SMA families. Other items have been purchased with funding that Cure SMA receives specifically to purchase certain items for the equipment pool. A list of some items found in the equipment pool include:

- Car Beds (Infant Cosco Car Bed and the Hope Car Bed)
- EZ-on vests
- Bath chairs
- Medical strollers
- Manual wheelchairs
- Stenders
- Therapy and positioning devices

Call the Cure SMA office at 800.886.1762 or e-mail [equipment@curesma.org](mailto:equipment@curesma.org) for more information.



## Local Support Through Cure SMA Chapters

Our Chapters make it their mission to support families and fundraise for SMA, giving hope to families in their community. Chapter fundraisers include Walk-n-Rolls, golf tournaments and gala events. Chapter support includes providing resources to families affected by SMA, linking families together for mutual support, and providing public awareness in their communities for a wider awareness of SMA.

We are always available if you want to talk with others who understand. Cure SMA has numerous chapters throughout the US, as well as networking programs that link families together for mutual support. Please contact us at any time!

Visit our website at [www.cureSMA.org](http://www.cureSMA.org) or call 800.886.1762 to get connected with your local chapter.

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# The Annual SMA Conference

Every year, Cure SMA sponsors a conference to bring together the leading SMA researchers, clinicians, and families living with SMA. Cure SMA has been hosting the Annual SMA Conference since 1989. The weekend is filled with a wide variety of workshops, a memorable children's program, a family fun fest and carnival, many opportunities to connect and interact with families and receive first hand updates from the researchers. Every year, we look forward to reuniting as a community at this conference and showing our support for others. As always, the family and the research conferences run alongside each other. 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 it for those affected by SMA. The interactions between the researchers and families at this one conference are extremely special. The annual conference also provides these children an opportunity to make new friends and have a great time.

## **The Goals of the SMA Conference:**

- 1) To allow networking between researchers, medical providers, patients and families
- 2) To educate researchers on the latest research advancements
- 3) To attract the best researchers to the SMA field and encourage collaborations
- 4) To educate patients and families on the basics of SMA
- 5) To update patients and families on the latest research and medical progress



## **CONTINUING MEDICAL EDUCATION CONFERENCE**

Cure SMA has introduced a new component for medical professionals at the Annual SMA Conference. A conference is now held prior to the start of the Annual SMA conference and researcher conference. The CME conference, titled “Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role”, for medical professionals, is the first of its kind for Cure SMA. The conferences have previously covered two components of SMA: research and support. The research aspect covered scientific, research & clinical updates, while the support aspect included the family support workshops and family networking. The addition of this conference provides an exciting new third component of Care to the Cure SMA Conferences by educating medical providers on SMA. Cure SMA partners with an accredited hospital who can provide continuing medical education credits for medical professionals, and offers a full day of lectures and educational materials to all attendees.

## **NEWLY DIAGNOSED CONFERENCE PROGRAM**

Thanks to the generous funding provided by the Erin Trainor Memorial Fund, Cure SMA covers the registration fees for the Annual SMA Conference for all families newly diagnosed since the last conference. The mission of the Erin Trainor Memorial Fund (ETMF) is to generate substantial funds to be able to provide conference scholarships, allowing newly diagnosed SMA families/individuals the opportunity to attend the Annual SMA Conference. 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 Cure SMA.

## **CONFERENCE SCHOLARSHIP PROGRAM**

Financial need scholarships are also available to assist SMA families in attending the conference, who do not qualify for the Newly Diagnosed Program. This program allows families who may not be able to financially afford attending the conference, the opportunity to apply to this program and receive financial aid, in the hopes that by waiving their registration fees, they may be able to attend the conference.

# About Cure SMA

Cure SMA is dedicated to the treatment and cure of spinal muscular atrophy (SMA)—a disease that takes away a person’s ability to walk, eat, or breathe. It is the number one genetic cause of death for infants.

Since 1984, we’ve directed and invested in comprehensive research that has shaped the scientific community’s understanding of SMA. We are currently on the verge of breakthroughs in treatment that will strengthen our children’s bodies, extend life, and lead to a cure.

We have deep expertise in every aspect of SMA—from the day-to-day realities to the nuances of care options—and until we have a cure, we’ll do everything we can to support children and families affected by the disease.

Learn more about how you can help us reach a treatment and cure at [www.cureSMA.org](http://www.cureSMA.org).



## **Cure SMA**

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We’re on the Web!  
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