



CURE SMA

CARE SERIES BOOKLET

A SOURCE OF INFORMATION AND SUPPORT FOR INDIVIDUALS LIVING WITH SPINAL MUSCULAR ATROPHY AND THEIR FAMILIES.

COMMUNITY SUPPORT SERVICES



Make today a
breakthrough.



WELCOME TO THE CURE SMA COMMUNITY

The diagnosis of spinal muscular atrophy (SMA) can be confusing, scary, frustrating—pretty much the whole gamut of emotions. But you are not alone. You are now part of the Cure SMA community—a network of individuals, families, researchers, clinicians, and other health professionals who are determined to make a difference in the quality of life for those impacted by SMA.

Founded by a group of SMA parents in 1984 as a support group for families of children with SMA, Cure SMA is a resource for unbiased support and we are here for you at whatever level you need. We offer the best, most accurate information about SMA, the chance to connect you with others who are impacted by SMA, as well as resources and support to assist in your care or the care of a loved one with SMA.

We support every type of SMA and every affected person—from newborns to adults to families who have lost a child. We also support people who are carriers of the SMA gene, helping them understand the implications and explore options. No matter your connection, we're committed to being an irreplaceable resource for anyone facing SMA and we're doing everything we can to improve quality of life for everyone affected by the disease so you can live active, engaged, and hopeful lives.

This booklet outlines many of the invaluable resources and support programs Cure SMA offers. We also have chapters throughout the U.S., run by dedicated volunteers, many of whom are individuals with SMA or their family members. These committed and experienced individuals are available to provide support and advice on a local level.

Please do not hesitate to contact us anytime at communitysupport@curesma.org or 800.886.1762.

If you know someone who has been recently diagnosed with SMA, please email infopack@curesma.org.

We will overnight a comprehensive informational packet on SMA and ensure you know about all the resources and support programs available.



STAY CONNECTED TO CURE SMA

There are many ways that you can stay connected with Cure SMA and stay informed about the latest in SMA treatment, care, advocacy, and resources. Below are just a few ways offered—online, by mail, or in person.

Virtual Community Engagement Events

Cure SMA has implemented a range of virtual events for the SMA community to connect with the community from the safety and comfort of your own home. Opportunities include webinars, adults with SMA socials and family socials.

Visit www.curesma.org/community-engagement-events/ for a list of upcoming virtual events

Cure SMA Website

Our website provides the latest in news, research and treatment information, educational and fundraising events, and SMA community stories. The dynamic site is reviewed frequently to ensure the information you are receiving is both up-to-date and accurate.

Visit <https://www.curesma.org/> for the latest news and information, and check out the “Find a Location” tool to identify a treatment site and/or event site near you, available at <https://www.curesma.org/find-a-location/>.

Directions Newsletter

Our biannual newsletter builds our community by sharing updates, stories, and experiences.

Directions contains articles on daily living, letters and stories from the community, information on events, and more.

Past issues of *Directions* are all available for download online at the following link:
<https://www.curesma.org/directions-newsletter/>.

Compass Newsletter

Compass is a regular Cure SMA newsletter focused on research and clinical care updates, highlighting all of the major research developments and clinical best practices.

Past issues of *Compass* are all available for download online at the following link:
<https://www.curesma.org/compass-newsletter/>.

E-News Distribution List

You can sign up for our e-news distribution list to receive regular emails with the most up-to-date information, events, and happenings within the SMA community.

Request to be added by emailing info@curesma.org.

Social Networks

Cure SMA social networks are a great place to receive updates on anything and everything SMA related. It is also a wonderful place to network with many individuals and SMA families worldwide.

Twitter: twitter.com/cureSMA | Instagram: [@curesmaorg](https://www.instagram.com/@curesmaorg) | Facebook: [facebook.com/cureSMA](https://www.facebook.com/cureSMA) | Youtube: [youtube.com/user/FamiliesofSMA1](https://www.youtube.com/user/FamiliesofSMA1) | LinkedIn: www.linkedin.com/company/families-of-sma

CARE SERIES BOOKLETS

Our SMA Care Series Booklets cover a range of topics on SMA and are meant to provide you with information needed to make decisions about treatment and care. Each booklet is written by SMA experts to ensure the quality and accuracy of information. Many of these booklets are also available in several different languages.

Understanding SMA

Covers all the basic information you need to know about SMA, including genetics of the disease, diagnosis, types, daily life, and much more.

Breathing Basics

Looks at aspects of respiratory care with SMA, including respiratory care management, common respiratory issues, and equipment.

Nutrition Basics

Explores the nutrition principles for someone living with SMA, potential complications, feeding tubes, and more.

Musculoskeletal System

Helps provide a better understanding of how SMA can affect the body's musculoskeletal system.

Genetics of SMA

Offers clarity around the genetics of SMA and its diagnosis, helping to navigate complex conversations.

Mental Health Management

Addresses complex mental and emotional health topics when facing life with a chronic illness, such as anxiety, depression, and coping mechanisms.

Caring Choices

Covers topics for all ages and stages of SMA, including supportive care and treatment options, care coordination, and palliative care.

Understanding Insurance Coverage

Addresses common insurance-related questions, including guidance on talking to insurers about treatment.

About Clinical Trials

Explains topics such as the clinical trial process and participation, and accelerated approval and expanded access.

Considering Drug Combinations

Looks at the important considerations when thinking about combination therapy now and in the future.

Newborn Screening Diagnosis

Provides a foundation for understanding SMA if you are learning about an SMA diagnosis through newborn screening.

Living Unlimited: Newly Diagnosed

This booklet is for new members of the SMA community experiencing an SMA diagnosis for the first time and wondering how it will impact the life of their child and that of the family.

If you would like to receive hard copies of any of these publications, please email communitysupport@curesma.org. They are also available for download on the Cure SMA website at the following link: <https://www.curesma.org/care-series-booklets/>.

INFORMATIONAL PACKETS ON SMA

The SMA Information Packet is one of the primary ways Cure SMA supports all members of the SMA community. Packets are available to anyone who requests one, at no charge.

The packet includes:

- Information about SMA;
- The SMA Care Series Booklets;
- Timely information on clinical trials;
- Details about the Annual SMA Conference;
- Research news, and more.

About a month after you receive the Information Packet, you will also receive a selection of past issues of *Directions*, our biannual Community newsletter.

Anyone can request an SMA Information Packet by emailing infopack@curesma.org or by calling the national office at 800.886.1762.

People requesting a packet of information could include, but are not limited to:

- Newly diagnosed individuals and families wanting to learn about SMA, and the programs and services offered to support them.
- Families or individuals not newly diagnosed who are looking for more comprehensive information on SMA.
- Relatives, friends, or supporters of someone with SMA who want to learn more about the disease.
- Healthcare providers—including doctors, nurses, therapists, nutritionists, etc.—or healthcare students in training, who want to raise the standard of care for those affected by SMA.

We are continually updating our SMA Information Packet to bring you the most timely and useful information on SMA. Feel free to reach out if you are unsure you have the information.



CHILD CARE PACKAGES



Newly Diagnosed Care Packages

Cure SMA automatically sends a care package to every newly diagnosed family who contacts Cure SMA that lives in the U.S. The care package also includes a Cure SMA Medical Binder, which serves as an organizational tool to keep important paperwork all in one location. These care packages are filled with toys and helpful items that have been recommended by other SMA parents. Each care package is sent based on the type of SMA a child has and the age of the child. Not every item included will be age appropriate right away, but they can be used as your child gets older and are meant to serve as ideas on toys and activities that have worked well for other families at different ages and stages. The contents of our care packages change regularly as new items are donated or suggested.

If your child was recently diagnosed with SMA, please email infopack@curesma.org so we can get an SMA Information Packet and care package sent out to you right away.



Wagon Program

Cure SMA offers a wagon to every SMA family who requests one. Wagons are a part of our care package program and are sent brand new and at no charge for each family to keep. These wagons are beneficial for children with both early and later onset SMA of all abilities, and are ideal for parents to be able to transport their child without the use of a stroller or wheelchair.

For more information about how to receive a wagon, please contact the Cure SMA office at 800.886.1762 or email us at communitysupport@curesma.org.

TEEN & ADULT PACKAGES

Like our care package program for infants and children, our teen and adult packages are offered specifically for teens and adults living with SMA.

Teen & Adult Support Package

The original package for teens and adults that is filled with helpful items that allow for increased independence and that have been recommended by other adults with SMA. Items include a medical fleece ease sheepskin, Amazon Echo, telescopic back scratcher, long reacher grabber tool, gooseneck phone or tablet mount, remote control outlet switch kit, EZ-shampoo hair washing basin, neck and shoulder heating pad, and a fluidized positioner pillow.

[Link to Apply for Support Package: www.curesma.org/SupportPackage](http://www.curesma.org/SupportPackage)

Teen & Adult Independence Assistance Package

A supplemental package for teens and adults with SMA that is filled with a new set of helpful items to help gain further independence with activities of daily living. Items include Logitech Blue Snowball Microphone, WiFi smart plugs, travel UV sanitizing wand, universal cup holder, telescopic metal straws, jar opener with base pad and a multi kitchen tools set.

[Link to Apply for Independence Assistance Package: www.curesma.org/IndependencePackage](http://www.curesma.org/IndependencePackage)

Please note you must have a confirmed SMA diagnosis, be 13 years of age or older, live within the U.S., and have not already received a support package through this program to qualify.



EQUIPMENT LOAN POOL



Individuals with SMA may require specialized care and equipment, which can put enormous financial pressure on themselves or their families. In response, Cure SMA operates an equipment loan pool that gives individuals and families affected by SMA access to specialized equipment at no cost.

Cure SMA has a collection of equipment suitable for both children and adults with SMA, including car beds, bath chairs, lightweight manual wheelchairs, therapy chairs, and medical strollers. These items are specifically focused on some of the critical equipment items that aren't always covered by insurance.



This loan service is available free of charge to all members of the Cure SMA community within the U.S. There is no time limit on how long an item can be borrowed through the equipment pool. We just ask that once the item is no longer needed that it be returned to the equipment pool in working order so it can be loaned out to another person or family.

Our equipment inventory changes often as new equipment is donated and other items are loaned out, so we encourage patients to contact us at equipment@curesma.org to find out availability and to be put on a waiting list for items that aren't available upon request.



LIFEVAC SUPPORT PROGRAM

This support program is offered to all affected individuals with SMA to help in the event of a choking emergency. Through this program a LifeVac Home Kit is provided to any individual with SMA who requests one at no cost to this person.

The LifeVac Home Kit includes:

- (1) LifeVac non-powered, non-invasive airway clearance device
- (1) Adult mask
- (1) Pediatric mask
- (1) Practice mask



The LifeVac is a non-powered, non-invasive, single-use only airway clearance device developed for resuscitating a victim with an airway obstruction when current choking protocols have been followed without success. It is easy to use and is beneficial for those who the Heimlich maneuver is not possible.

To apply for LifeVac: www.curesma.org/LifeVac

Please note, you must have a confirmed SMA diagnosis, live within the U.S., and have not already received a LifeVac Home Kit through this program to qualify.

MEDICAL ALERT BRACELET



This support program is offered to all affected individuals with SMA to help identify their medical needs in case of a medical emergency. Through this program, a Responder PHR (Personal Health Record) with Medical Alert Bracelet and Keychain is provided so medical personnel will have immediate access to the patient’s medical records stored online, whether or not the patient is able to communicate for themselves. This includes prior medical conditions, allergies, current medications, etc.

Each package comes with a waterproof, silicone Medical Alert adjustable bracelet and matching waterproof keychain. Also included is the option to customize two sets of engraved acrylic plates with the patient’s most vital health information. This engraved plate with instructions on how to retrieve personal medical information from the bracelet—is meant to be read at-a-glance by medical responders who need immediate access to the PHRs online. These can be easily accessed from any internet capable device such as a smartphone, tablet or any computer using a simple PHR-ACCESS login URL and secured with a unique Member ID number. The patient can also choose to give access to all records or select the health information they want to share stored within the online system.

If you are an individual with SMA or a legal guardian of a child with SMA, who is interested in receiving a Responder PHR with Medical Alert Bracelet and Keychain, you can request one by filling out the online form at the following link: www.curesma.org/ResponderPHR

Please note, you must have a confirmed SMA diagnosis, live within the U.S., and have not already received a Responder PHR with Medical Alert Bracelet and Keychain through this program to qualify.

The Responder PHR system also serves as an organizational tool and allows you to input personal information and previous health records into categories, including:

- Medical conditions
- Medications
- Allergies
- Emergency and doctor contacts
- Insurance information
- Immunization records
- Medical procedures
- Advance medical directives
- Living will
- Durable power of attorney
- Organ donor status
- Other pertinent info

MANAGING YOUR INFORMATION

Cure SMA Medical Binder

The Cure SMA Medical Binder acts as an organizational tool that allows patients to keep important medical documents and information about themselves or their child all in one location to help manage treatment and care needs. Having all of these important documents located in one place also makes it easy to grab in the event of an emergency.

To help patients get started, we include handouts with space and charts that can be filled in with vital information, medications, appointments, specialists, etc. The binder also includes eight (8) color-tabbed dividers and ideas for customizing the tabs. Patients can choose the topics that will be most helpful in managing their care or use blank stickers to come up with their own topics.

Within this binder, there is also a resource guide specific to the state you live in, as well as copies of Cure SMA's Care Series Booklets. These highlight important topics related to SMA care that may be important to bring up with your care team.

Every newly diagnosed care package automatically includes the Cure SMA Medical Binder. Anyone else interested in receiving a Cure SMA Medical Binder for themselves or their child can request one by filling out the online form at the following link: www.curesma.org/medicalbinder

The image displays several components of the Cure SMA Medical Binder. At the top is a 'MEDICATIONS' page with a table for tracking medications. Below it is a 'VITAL INFORMATION' page with fields for personal and medical details. To the right is a 'MEDICAL RECORD' page with a table for tracking surgeries. At the bottom is the front cover of the binder, which features a decorative pattern and the Cure SMA logo.

NAME OF MEDICINE	DOSE	FREQUENCY	DATE STARTED	DATE ENDED	NOTES

MEDICATIONS

Use this chart to track any and all medications, including vitamins and supplements. Include dates of when past medications were taken and how often current medications need to be taken, dosage, any side effects, etc... It's also very important to note any allergic reactions the patient may have to certain medications.

VITAL INFORMATION

Fill this page out and keep an updated copy in your binder. It's a helpful "cheat sheet" to take with you to new doctor appointments or in case of emergency.

Name: _____
Date of Birth: _____ Height: _____
Weight: _____
Blood Type: _____
Diagnoses: _____
Allergies: _____
Primary Doctor Name: _____
Primary Doctor Phone #: _____
Primary Doctor Address: _____
Primary Insurance Name: _____
Primary Insurance Policy #: _____
Primary Insurance Phone #: _____
Secondary Insurance Name: _____
Secondary Insurance Policy #: _____
Secondary Insurance Phone #: _____

MEDICAL RECORD

SURGERY TYPE	DATE	DOCTOR	LOCATION	NOTES

MEDICAL BINDER

cure SMA

LOCAL SMA SUPPORT

Summit of Strength Program

The Summits of Strength are educational events meant to provide information for people of all ages and types of SMA, as well as their loved ones and caregivers. These one-day “mini-conferences” give families, adults, and caregivers an opportunity to network and learn from national and local experts about the latest advances in treatment, care, advocacy, and support.

Each Summit offers a unique agenda of topics ranging from standard of care, research and clinical trials, navigating the special education process, stress management techniques, and much more! Along with the informative presentations, attendees can also meet their Cure SMA chapter leaders and connect with the rest of the local SMA community. This is a free program which includes breakfast, lunch, and parking for attendees.

To learn more and see if there is a summit scheduled near you visit <https://www.curesma.org/local-support/#summitofstrength>.



Cure SMA Chapters

Cure SMA has 36 volunteer chapters throughout the United States. Our chapters provide support for affected individuals and families through networking, fundraising events and advocacy. Our chapters make it their mission to support families and individuals affected by SMA and to fundraise for SMA, giving hope to the community.

Chapter fundraisers include Walk-n-Rolls, golf tournaments, and gala events. Chapter support includes providing resources to families and individuals affected by SMA, linking them together for mutual support, and providing public awareness in their communities for a wider awareness of SMA.

Chapter leaders are always available if you want to talk with others who understand. Please contact us at any time!

Visit our website at <http://www.curesma.org/chapters/> or call 800.886.1762 to get connected with your local chapter.



ANNUAL SMA CONFERENCE



Every year, Cure SMA sponsors a conference to bring together the leading SMA researchers, clinicians, individuals, and families affected by SMA. The Annual SMA Conference is the largest conference for SMA in the world and a wonderful opportunity for people from all over to meet, attend workshops, and receive the most up-to-date information on SMA. Additionally, the SMA Research & Clinical Care Meeting runs alongside the Annual SMA Conference, bringing together researchers, healthcare professionals, individuals with SMA, and families to network, learn, and collaborate.

The goals of the Annual SMA Conference and SMA Research & Clinical Care Meeting are to:

- Welcome newly diagnosed individuals and families into the SMA community;
- Help build an SMA community that is strong and unified;
- Inform SMA community of updates on medical issues, research, and clinical trials;
- Facilitate networking and data sharing between researchers, clinicians, families, and affected individuals;
- Educate researchers and clinicians on the latest research advancements;
- Attract the best researchers and clinicians to the SMA field, encouraging collaborations and investments; and
- Promote cross-disciplinary dialogue among academic, clinical, and industry researchers.



Conference Scholarships

Cure SMA offers a variety of scholarships to allow as many individuals and families affected by SMA as possible to attend and experience the benefits of this amazing conference. This includes scholarships for first time attendees, adults with SMA, and those with financial-based needs. Information on these scholarships is available on our website.



Conference Networking Opportunities

The Annual SMA Conference has something for everyone! In addition to opportunities to connect and interact with the SMA community and receive first-hand updates from researchers and clinicians, this special event features:

- Educational workshops.
- Keynote sessions with leading researchers and clinicians.
- Family-friendly poster session.
- Memorable children's program.
- Meet and greet with a family fun fest.
- Teen and adult social activities.
- PJ party and movie night.
- Dance party.



No matter your connection to the SMA community, there are unique networking opportunities such as a newly diagnosed session for recently diagnosed families; a teen social for teens with SMA; an adult social and special lounge for adults with SMA; and socials for both parents and grandparents.

In addition to separate networking opportunities, we also have many workshop sessions geared specifically for many members in the community, including but not limited to:

- Parents of both children and adults with SMA
- Adults with SMA
- Teens with SMA
- Children with SMA
- Grandparents
- Relatives
- Siblings
- Spouses
- Grieving families
- Friends



CURE SMA



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

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. Individuals and caregivers make different choices regarding what is best for their situation, consistent with their personal beliefs. Parents and other important family members should be able to discuss their feelings about these topics, and to ask questions of 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 individual and their caregivers.



Remember that your healthcare team and Cure SMA are here to support you. To continue learning, please see other available Care Series booklets:

- Breathing Basics
- Caring Choices
- Genetics of SMA
- Musculoskeletal System
- Nutrition Basics
- Understanding SMA



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www.linkedin.com/company/families-of-sma



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