

# IMPACT REPORT

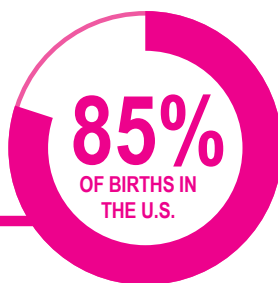
July 1, 2020 – June 30, 2021



Over the last 12 months, Cure SMA continued to make progress for all individuals with SMA and their families by advancing our research, advocacy, care, and support programs. These efforts were made possible by the hard work and dedication of the entire SMA community. We believe that no challenge is too large and together we will build a hopeful tomorrow for future generations of people with SMA. Below are just a few highlights and outcomes from last year.

## ADVOCACY:

Increased the number of states screening newborns for SMA to 38, accounting for



**2,400+** advocacy actions taken and **5,800+** messages delivered to federal and state legislators in support of SMA community advocacy priorities.

## RESEARCH:

Cure SMA-funded research led to the publishing of **22** journal articles.

**1,028**  
RECEIVED

responses for the 2020 SMA Community Update Survey, which helps inform Cure SMA's agenda in support of people with SMA and their families.

## COMMUNITY SUPPORT

**2,457** registrants for 2021 Virtual SMA Conference

**115** virtual programs held, with 22,000+ views of programs to date

**253** Newly Diagnosed Care Packages sent

**520** of original Teen & Adult Support Packages sent

**504** of new Teen & Adult Independence Assistance Packages sent

**327** pieces of equipment sent from our equipment pool

**1,095** COVID-19 PPE Packages sent

## CLINICAL CARE:



Expanded the numbers of participants in the SMA Clinical Data Registry to

**nearly 600,**

including both children and adults with SMA.

**INVESTED**  
**\$2.4 million**

in extending our connected network of U.S. research and care sites through the Cure SMA Care Center Network, Pediatric Neuromuscular Clinical Research Network, and SMA Clinical Data Registry.

Note: The figures above are taken from the 2020 fiscal year (07/01/2020-06/30/2021). Our complete financial information can be found at [www.curesma.org/annual-reports-financials/](http://www.curesma.org/annual-reports-financials/).

# IMPACT REPORT



Cure SMA is thankful for every gift we receive, and your support helps us grow the research, care, advocacy, and support programs that the SMA community depends on. Every dollar goes to...

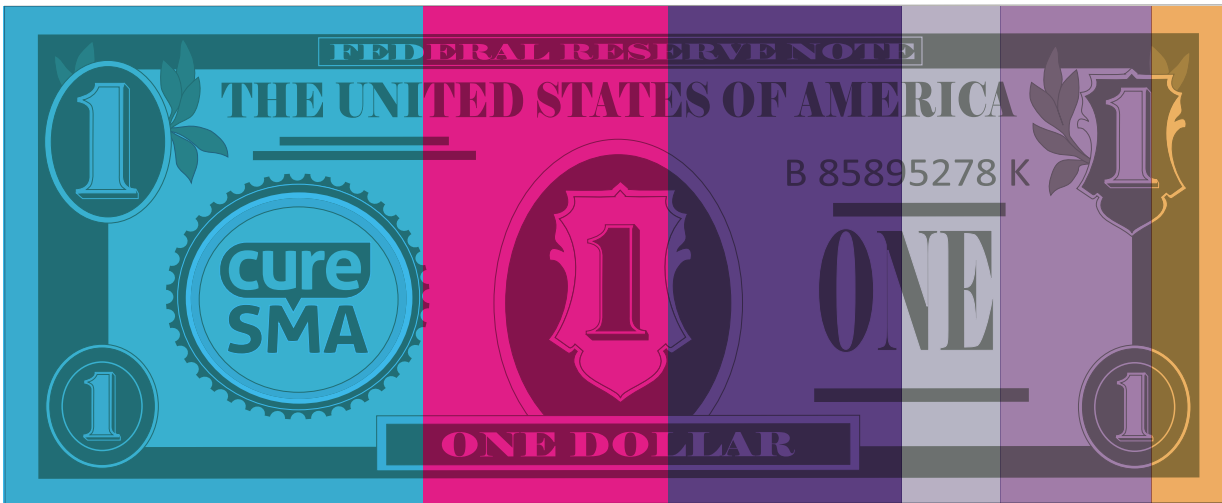
## RESEARCH 34%

to advance the development of combination therapies that will help everyone with SMA increase voice strength, improve mobility, and build the stamina needed to effectively participate at work and in school.

## CLINICAL CARE 20%

to continue gathering information from the Cure SMA Clinical Data Registry, track patient outcomes and treatment progression, and create an evidence-based standard of care for SMA.

## MANAGEMENT & GENERAL 8%



## COMMUNITY SUPPORT 19%

to grow our local presence and unite communities through support programs, ensure access to approved treatments, and create customized programs that meet the needs of everyone affected by SMA.

## AWARENESS 7%

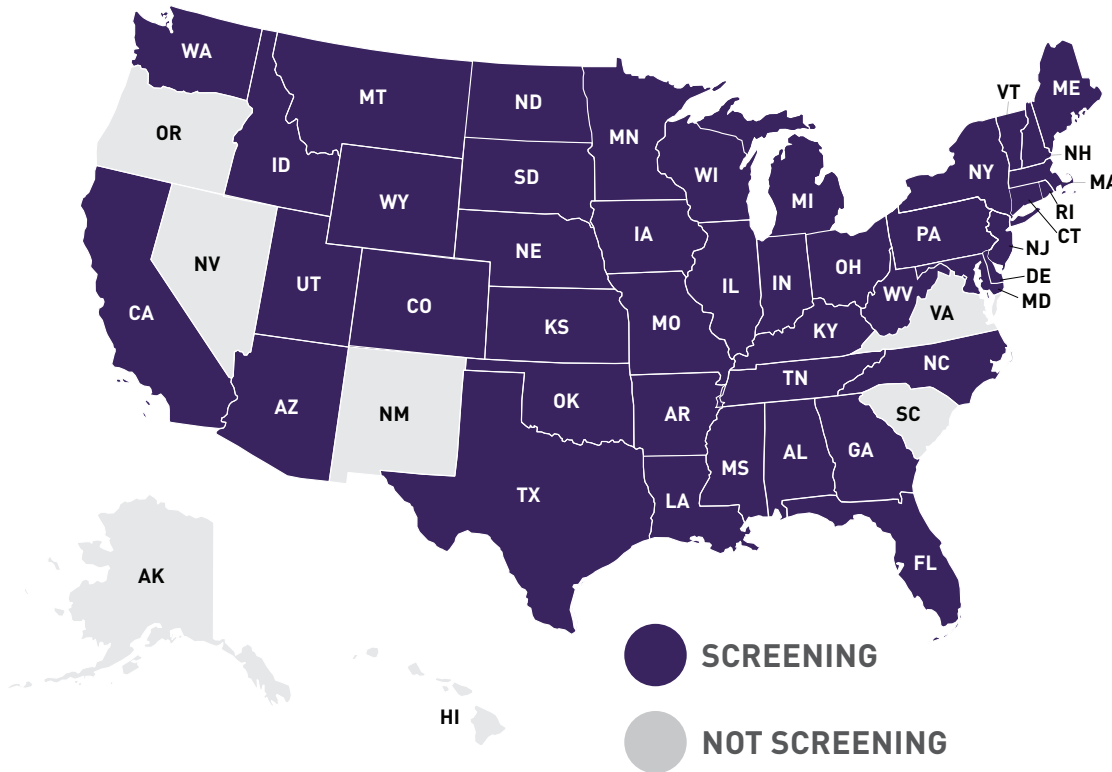
to advocate for access to care - including in-home care and personal care attendants, access to approved treatments, protections for COVID-19 vaccine allocation, and other needs for everyone with SMA.

## FUNDRAISING 12%

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# STATES SCREENING & NOT SCREENING FOR SMA

43 States Currently Screen for SMA | 92% of Newborn Babies in the U.S. are Screened



## IMPLEMENTER

Alabama  
Arizona  
Arkansas  
California  
Colorado  
Connecticut  
Delaware  
Florida  
Georgia  
Idaho  
Illinois  
Iowa  
Indiana  
Kansas  
Kentucky  
Louisiana  
Maine  
Massachusetts  
Maryland  
Michigan  
Minnesota  
Mississippi  
Missouri  
Montana  
Nebraska  
New Hampshire  
New Jersey  
New York  
North Carolina  
North Dakota  
Ohio  
Oklahoma  
Pennsylvania  
Rhode Island  
South Dakota  
Tennessee  
Texas  
Utah  
Vermont  
Washington  
West Virginia  
Wisconsin  
Wyoming

## SCREENING STATES

Since 2018, 43 states have implemented permanent or pilot SMA newborn screening programs, assuring that every baby born in their states is screened. This provides parents the information they need to make the rights decisions about treatment and care if their child is diagnosed with SMA.

**IMPLEMENTER STATES (43)** These states have implemented permanent screening programs for SMA and have led the way in newborn screening. Today, because of their hard work, they have helped achieve Cure SMA's goal of reaching half the country within 2 years of the federal recommendation for SMA screening!

**Fun fact:** California, Illinois, Washington, Montana, Maine, and Texas are some of the latest to join the ranks as "Implementer" states.

**Fun fact:** approximately 92% of babies born in the U.S. are screened thanks to "Implementer" states!

## NON-SCREENING STATES

Despite the progress in screening newborns for SMA, **the U.S. remains well short of the 100% implementation target.** [Cure SMA](#) urges these states to expedite adoption and full implementation of newborn screening for SMA. This is especially important given the availability of disease modifying, life-saving treatments for SMA.

**ALMOST THERE STATES (1)** These states are in the final steps toward permanent implementation of newborn screening of SMA. They have made strong progress and are taking final steps to implement their SMA newborn screening program, but every day counts as they work to ensure babies born in their state are screened for SMA.

**Fun fact:** after full implementation by the "Almost There" states, close to 9 in 10 babies in the U.S. will be screened for SMA.

**ACTION REQUIRED STATES (7)** Three years following the federal recommendation, these states are still not screening their newborns for SMA. Many of these states have taken promising steps while other states are at-risk of being the last adopters of newborn screening of SMA in this country. Additional action is required to catch up with the screening states.

**ALMOST THERE**  
Virginia

## **ACTION REQUIRED**

Alaska  
Washington, DC  
Hawaii  
Nevada  
New Mexico  
Oregon  
South Carolina

\* Opt-in Pilot  
\*\* Population Study

Last updated February 2022

# SPONSORSHIP COACHING



Sponsorships can help you take an event to newer heights but can feel intimidating when you are not sure where to start. Below you will find some helpful information regarding stewardship and research.

## WHAT IS SPONSORSHIP?

**Sponsorship Defined-** When an entity commits to providing resources or monetary support in exchange for predetermined benefits. Ex: Business A sponsors your event for \$- and will receive their logo on a yard sign at the event site on event day.

## TYPES OF SPONSORSHIP

- **Monetary:** Supports an event financially.
- **In-Kind:** Supports an event through provided goods and/or services.
- **Promotional:** Supports an event through advertising and promotion.

## WHO TO APPROACH?

The simplest place to start is locally with businesses and individuals in your personal network. This can include, but is not limited to, family, friends, employers, businesses you frequent, and groups you are involved in (church, support groups, athletic teams, social organizations, etc.) Communicate your goals and see if they would be interested in supporting your fundraising efforts. This can have a ripple effect when you invite your network to engage their networks.

## SPONSORSHIP PERKS\*\*

What types of recognition can you offer to your sponsors?

*Facebook posts, signage, an opportunity to speak at your event. The most important part of thinking of benefits is knowing who your audience is and how they relate to the sponsor you are approaching. This will help you find mutual benefits and be the best possible outcome for all members of an event.*

## SPONSORSHIP TRACKING

Keep track of who you solicit and their interest. It will be beneficial to you to then keep track of when sponsors pay and help you ensure all committed sponsors are donating to your event.

## DELIVERABLE DISCLAIMER

Keep the same

## SPONSORSHIP PITCH EXAMPLE

Hello \_\_\_\_\_,

I am hosting/ attending an event benefiting Cure SMA (Spinal Muscular Atrophy). (Mention more about event here)

SMA impacts the lives of thousands of people and Cure SMA is an irreplaceable resource. By providing services like care packages for newly diagnosed families, teens, and adults, local Summit of Strength programs, an equipment pool, and the Annual SMA Conference. I hope you will consider supporting my efforts by sponsoring our event.

**\*\*BENEFITS YOU CAN OFFER. \*\***

Best,

YOUR NAME



# IN-KIND DONATION FORM

Primary Contact Name(s): \_\_\_\_\_

Business Name (If applicable): \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_ Website: \_\_\_\_\_

Donated Item(s) Include: \_\_\_\_\_

Total Value: \$ \_\_\_\_\_ Date: \_\_\_\_\_

## PLEASE MAIL FORM AND DONATED ITEM(S) TO:

Cure SMA  
925 Busse Rd  
Elk Grove Village, IL, 60007

- Gift Certificate(s) or item(s) are enclosed
- I will deliver item(s) by \_\_\_/\_\_\_/\_\_\_ to (contact name): \_\_\_\_\_
- Please pick up item(s)/cash donation on \_\_\_/\_\_\_/\_\_\_ at (location): \_\_\_\_\_

*Cure SMA is a 501(c)(3) non-profit organization. Your contribution is tax deductible to the extent allowed by law.  
Donor information is not shared or sold to any outside organizations.*

*Please keep a copy of this letter for your records and for tax purposes. Federal ID# 36-3320440.  
For more information about Cure SMA, please visit [www.cureSMA.org](http://www.cureSMA.org).*