2023 ANNUAL REPORT

cure SMA

VISION AND MISSION STATEMENT

Cure SMA leads the way to a world where everyone impacted by spinal muscular atrophy is empowered to lead independent, successful, and fulfilling lives. We strive to create a community where every individual is heard and feels welcomed. Cure SMA provides practical support programs for our community and advocates for their needs. We fund and direct comprehensive research that drives breakthroughs in treatment and we advance access to high-quality care.
We will not stop until we have a cure.

OUR VALUES

Innovation

Our commitment to a treatment and cure is not just about seeking solutions—it's also about creating them. We're working with some of today's sharpest minds to advance a diversity of approaches and champion the most promising discoveries and methods.

Balance

As relentlessly as we pursue a treatment and cure, we are also strategic. We know the fastest way to a future without SMA is to take a comprehensive, unbiased approach to research and maintain a balance of optimism and realism.

Collaboration

Our community is everything to us. We would not have made it this far in our fight without the invaluable contributions of our researchers, doctors, and families. Together, we are—and always will be—stronger than SMA.

Respect

There is no "right way" to live with a disease like SMA. Every person's experience is different, and it's every family's right to decide what SMA means for them.

Compassion

Thanks to the Cure SMA community, no person is ever alone in facing this disease. We offer unconditional support to people with SMA and their families, and communicate openly and honestly, giving them clear and accurate information.

Determination

Our work is not done until we have a treatment and cure, and we'll remain strong in our fight no matter what challenges come our way.

OUR COMMITMENT TO DIVERSITY, EQUITY, AND INCLUSION

Cure SMA works to create, nurture, and sustain an inclusive culture, where differences in life experiences and perspectives are embraced, and provides the foundation for new knowledge sharing and education that drives innovative solutions to meet and exceed the needs of our Cure SMA community and team members.

Dear SMA Community,

Cure SMA's 2023 Annual Report presents an opportunity for us to look back at the progress we've made through your ongoing support and commitment, which includes major milestones in multiple clinical trials that have reached full enrollment in the final stages.

However, we are also looking ahead toward future breakthroughs. From increasing strength, to independent living, to access to improved care—and ultimately to a cure—there is still much work to be done.

The landscape of SMA continues to evolve and expand, and so do the needs of our community. Thanks to you, significant milestones have been achieved, including the development of three powerful therapies and the implementation of newborn screening for 100% of U.S. births.

Throughout 2023, multiple in person events were held giving us the opportunity to connect the SMA community. The Annual SMA Conference in Orlando was our biggest conference ever with 3,200 attendees. We hosted more than 60 fundraising events, including our local community-based Walk-n-Roll program, Endurance events, Special Events, and more. We also held more than 22 of our educational and community update-focused Summits of Strength in cities across the U.S.

A key giving campaign in 2023 was our partnership with the Erin Trainor Memorial Fund (ETMF), started by Barb and Gene Trainor who lost their five-month-old daughter, Erin, to SMA 30 years ago. In the lead up to our Annual Conference and during the Opening Session, the ETMF generously matched all gifts made to the Cure SMA Care Center Network in an effort to add new Care Centers. Thanks to all who donated, $295,000 was raised and then matched by the Trainors for a total of $590,000 for the Care Center Network!

A key area of focus in FY2024 is an increase in basic research funding. Thanks to the generosity of our donors, sponsors, and community members, we are increasing our total funding going toward basic research grants to over $750,000, an increase of more than $250,000 over the prior fiscal year. The aim is to advance research to discover new non-SMN therapies and combination treatment approaches to gain the knowledge and understanding to help restore muscle strength and function.

Finally, we continue to be focused on the daily living needs of people with SMA. Whether it is a lack of accessibility or the desire for greater independence, our support programs and advocacy initiatives make a difference today.

The achievements highlighted throughout this report are a direct result of the hard work and dedication of our entire community—individuals with SMA, their families, clinicians, researchers, industry partners, sponsors, and donors.

Thank you for all you do, we are here today because of you and your continued support.

Sincerely,

Kenneth Hobby
President

Nick Farrell
Chairman of the Board


COMMUNITY SUPPORT

NATIONAL SUPPORT

Each year, Cure SMA provides families affected by SMA with resources to help them live independent, successful, and fulfilling lives. These programs provide tangible support for families affected by SMA, easing the difficulties of an SMA diagnosis, and showing each family that they are not alone. Our national support programs are available to all people affected by SMA who reside in the U.S. Most of these resources are provided at no cost to those affected by SMA.

- Information packets are available for newly diagnosed families, relatives, or friends, as well as healthcare providers looking to raise the standards of care for those affected by SMA.
- Care packages for newly diagnosed children are sent automatically and filled with toys and helpful items that have been recommended by other SMA parents.
- Support packages are available upon request for teens and adults with SMA that include items recommended by other adults living with SMA, including ones that allow for increased independence with certain tasks they might not have been able to do on their own.
- An equipment pool where Cure SMA loans, free of charge, necessary equipment, such as adaptive strollers, wheelchairs, car beds, standers, and more.

LOCAL SUPPORT

Local events foster greater connections in the SMA Community.
As the largest organization dedicated to SMA, Cure SMA is uniquely positioned to not only leverage the community's collective strength for a national impact, but also empower its 36 chapters across the country to offer personalized, local support to each individual and family affected by SMA. Whether joining a Walk-n-Roll, special event, or organizing a local Family Social, chapters offer a variety of ways to connect as a community.

In late 2018, Cure SMA launched the Summit of Strength Program—a series of single-day, educational events providing information for people of all ages and types of SMA, as well as their loved ones and caregivers. These mini-conferences allow attendees the opportunity to network and learn from national and local experts about the latest advances in support, treatment, care, and advocacy. Along with the informative presentations, attendees can connect with the rest of the local SMA community. This local engagement further strengthens the bonds that make our communities so vibrant! Over the past six years (including a long break due to COVID-19), Cure SMA has hosted 95 Summits of Strength, reaching over 6,000 registered attendees.

2,410
Support Items Sent

204
Newly Diagnosed Care Packages Sent

157
Packages Sent to Adults with SMA

3,200
Families, Individuals with SMA & Researchers at Annual SMA Conference

22
Summit of Strength Local Events Held Nationwide



ANNUAL SMA CONFERENCE

Cure SMA's Annual SMA Conference is the largest SMA conference in the world, bringing together researchers, healthcare professionals, families, and adults to network, learn, and collaborate. It is the centerpiece of our national support program. The 2023 Annual SMA Conference at Disney's Yacht & Beach Club Resorts in Orlando, Florida, was an impactful weekend filled with community, research, care, and—most importantly—fun for the more than 3,200 attendees – our largest conference to date!

The four-day weekend included a variety of workshops, research discussions, and special events for all attendees – children, teens, and adults. The Conference began on Thursday with the Newly Diagnosed Program, Meet & Greet, and Researcher Relay Race. These events brought together new and returning families, clinicians, and researchers (as well as a host of Disney characters) in a fun, relaxed setting before the start of conference workshops. The weekend brought over 63 workshops on various topics as well as the Family Friendly Researcher Poster Session, where families had direct access to the latest information about research, and researchers had the opportunity to build personal connections with the patients who will benefit from their work.

In addition to these educational opportunities, conference attendees were given the chance to unwind, engage, and have fun through activities such as the Family PJ Party & Movie Night, an Evening in the Park, a variety of socials for teens, adults with SMA, moms, dads, grandparents, and more!


CURE SMA RESEARCH & CLINICAL CARE MEETING

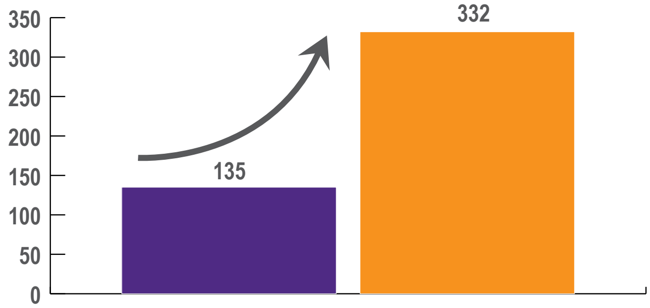
The Annual SMA Research & Clinical Care Meeting is held each year alongside the Annual SMA Conference and provides opportunities for networking with research and clinical care colleagues from around the world as well as patients and families between sessions and evenings. The 2023 SMA Research & Clinical Care Meeting was held June 28-30, 2023 at Disney World with over 630 attendees. Sessions included Musculoskeletal Complications and Implications, Mapping the Trajectory of a Treated Patient, and What We Have Learned in the Last Year, and offered 5.5 credit hours of CME/CE; a special session titled, "The State of SMA: Toward Improved Therapeutics and Care", Basic Research; Clinical Research, Clinical Drug Development; and poster sessions.

ADVOCACY

The purpose of Cure SMA Advocacy is to educate federal and state policymakers about the everyday living challenges of individuals with SMA and their families and to engage the SMA community in support of SMA-related policies.

During the fiscal year, Cure SMA Advocacy increased advocacy engagement around SMA community priorities:

- Nearly doubled the number of Cure SMA Advocates, including tripling the number of adults with SMA, with advocates in all 50 states

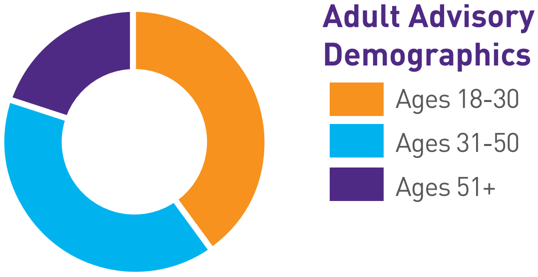


Grown advocate list from 135 to 332 adults with SMA

Other notable accomplishments during the fiscal year included:

- Secured advocacy wins for the SMA community, including new SMA research at the National Institute of Health, insurance coverage of seat elevation systems in power wheelchairs, and the implementation of newborn screening of SMA in the District of Columbia and South Carolina
- Expanded the Adult Advisory Council to 20 adults with SMA who provide high-level advice and feedback on Cure SMA activities to serve the SMA adult community

Adult Advisory Council Demographics



INCREASED ADVOCACY ACTION

3,470 Congressional messages sent

15 Advocacy campaigns launched

300 Cure SMA congressional statements released

- 72 fact sheets
- 25 sign on letters
- 58 Hope on the Hill letters
- 95 cosponsor letters
- 6 informational videos
- 18 coalition letters
- 26 NIH research language submissions

59 Participated in advocacy meetings

- 11 Hope on the Hill meetings
- 13 Air Travel meetings
- 35 coalition meetings

535 Members of Congress Contacted

CONGRESSIONAL SPEAKERS

Hosted U.S. Senator Amy Klobuchar of Minnesota, U.S. Senator Roger Wicker of Mississippi, and U.S. Representative Gus Bilirakis of Florida at Cure SMA's 11th Annual Hope on the Hill event in Washington, D.C.


U.S. Senator
Amy Klobuchar
of Minnesota


U.S. Senator
Roger Wicker
of Mississippi


U.S. Representative
Gus Bilirakis
of Florida

AIR TRAVEL REPORT

Published The Good, but mostly Bad and Ugly of Air Travel Report, showcasing over 150 air travel experiences from the SMA community, and shared this report with the U.S. Department of Transportation and every Member of Congress.


BUT MOSTLY,

THE GOOD, BAD AND UGLY OF AIR TRAVEL FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY

ADVOCACY VIDEO SERIES

Released a six-part Do It Yourself Advocacy Video Series to help individuals with SMA and their families learn how to advocate with their Members of Congress.


How to Structure a Congressional Meeting

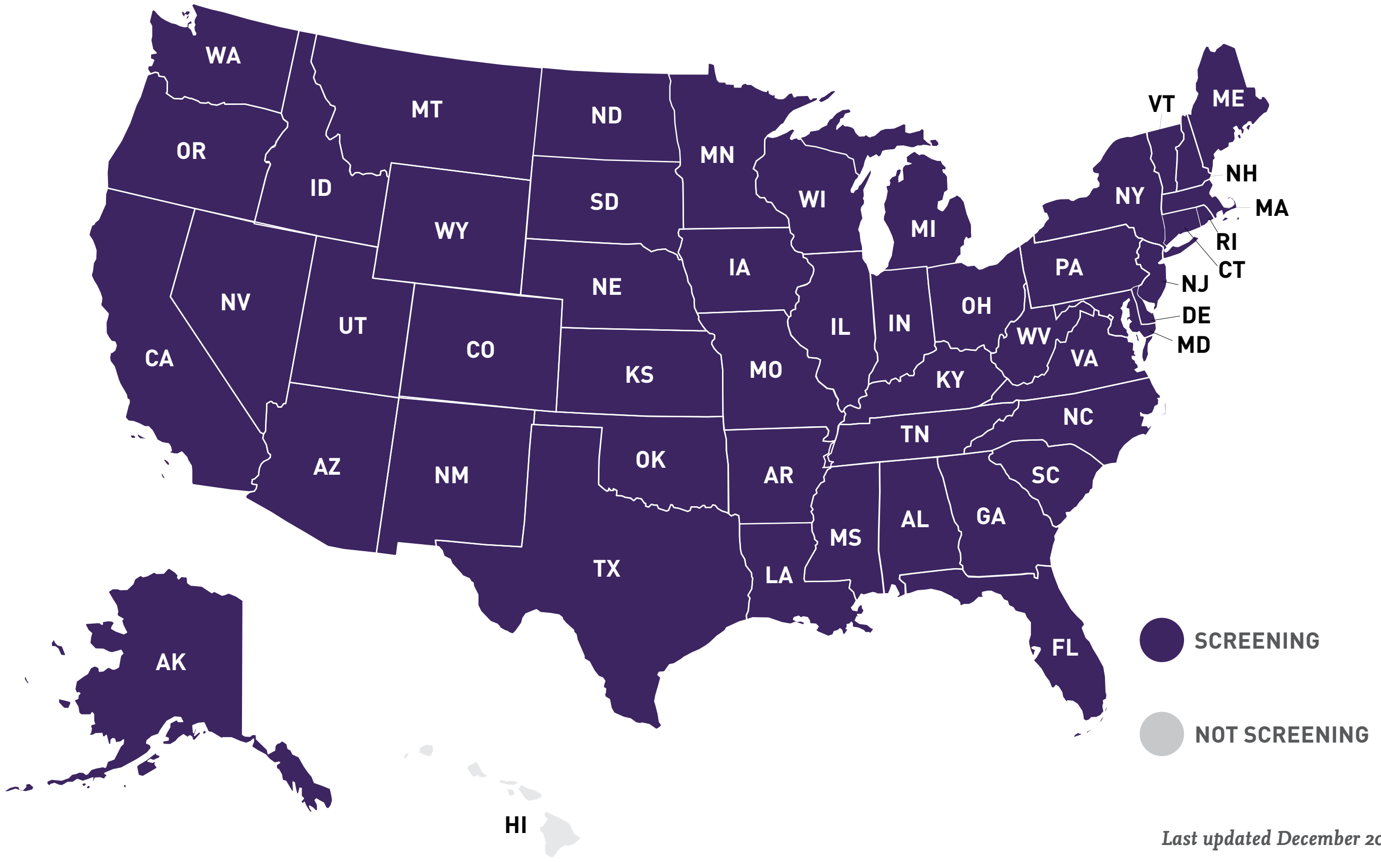

Sign Up & Take Action as a Cure SMA Advocate


NEWBORN SCREENING

In July 2018, the federal government added spinal muscular atrophy (SMA) to the Recommended Uniform Screening Panel (RUSP), the list of suggested conditions that states should screen for within their statewide universal newborn screening programs. Within 6 years of SMA being added to the RUSP, Cure SMA and its advocates have ensured that 100% of babies born in the U.S. are now screened for SMA at birth. Universal newborn screening of SMA means that infants born in any of the 50 states will no longer experience the frustration of delayed diagnosis and missed opportunities for better outcomes. We could not have accomplished this important goal without the support and advocacy of the SMA community – we celebrate this win with all of you.

STATES SCREENING & NOT SCREENING FOR SMA

49 States Currently Screen for SMA | **98%** of Newborn Babies in the U.S. are Screened



Last updated December 2023

At the start of the 2024, we reached our goal of 100 percent newborn screening for SMA in all 50 states!

CLINICAL RESEARCH & CARE

CURE SMA CARE CENTER NETWORK

To establish the best care, Cure SMA has partnered with hospitals across the U.S. to form the Cure SMA Care Center Network. These Centers are geographically diverse and represent a cross-section of care for individuals with SMA. Nearly half of these centers provide care to both pediatric and adult patients, four centers provide care focused on adults and 12 centers provide care focused on children.

We are not done! Cure SMA plans to expand the SMA Care Center Network from 29 to 60 centers across the U.S.

SMA CLINICAL DATA REGISTRY

The SMA Clinical Data Registry (CDR) is central to our work to collect data to then improve healthcare for people with SMA. Each SMA Care Center Network site consents patients with SMA to allow the center to submit information and data to the SMA CDR. This data is sourced from electronic medical records (EMR).

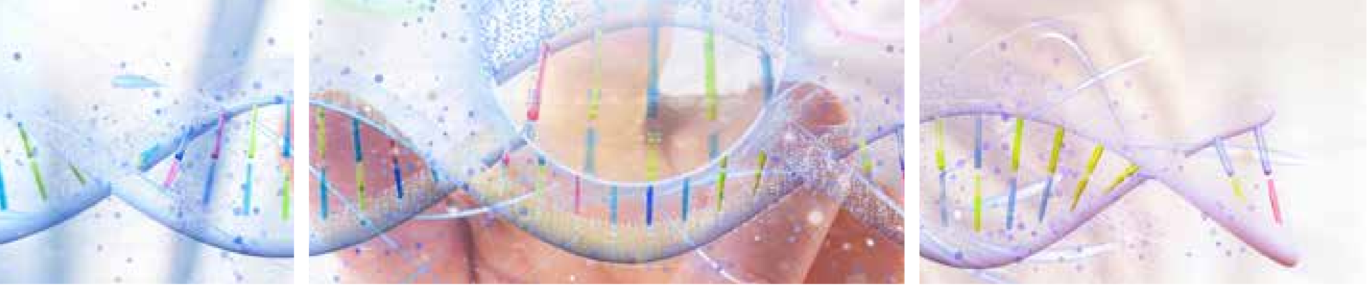
The ability to collect data on many representative individuals living with SMA in a registry is powerful. With more than 1,000 participants, the CDR is building a dataset to document changes in SMA over time. The CDR data is analyzed to drive care improvements. The analyses will be used to set the standard of care for SMA. Standard of care is treatment accepted by medical experts as a proper treatment for a specific disease or condition and widely used by healthcare professionals. The data-driven SMA standard of care guidelines will be distributed widely throughout the SMA community and to clinicians and hospitals caring for people with SMA. Keep in mind that data is more compelling than expert opinion.

CCN/CDR METRICS:

29
SMA Care Centers

22
States (and D.C.) with a Care Center

1,000+
patients' data in the SMA Clinical Data Registry



CURE SMA REAL WORLD EVIDENCE COLLABORATION

The Real World Evidence Collaboration was established to leverage the experience, expertise, and resources of pharmaceutical and biotechnology companies and nonprofit organizations involved in the development of SMA therapeutics to guide the future direction of real world evidence collection and use in SMA. Current members include Biogen, Genentech/Roche, and Novartis Gene Therapies.

The primary goal of the Real World Evidence Collaboration is to improve the quality and volume of real world data collection in SMA. Activities include supporting the infrastructure of the Cure SMA Clinical Data Registry (CDR), and the continued expansion of the SMA Care Center Network (CCN).

During FY23, the Real World Evidence Collaboration drove improvements to real world data collection for the SMA community. The Collaboration's accomplishments include:

- Conducting a CDR gaps assessment to identify opportunities for continued data improvement
- Publication of 2nd Annual State of SMA report
- Establishment of goals to support the improvement of quality metrics in the CDR
- Refinement of the Cure SMA Newborn Screening Registry survey to improve participant experience and allow for more efficient longitudinal data capture
- Completion of a survey to better understand the real-world structural components of SMA care delivery across the Care Center Network

STATE OF SMA

In early July 2023, Cure SMA launched its second annual State of SMA report. The purpose of this report was to share highlights from Cure SMA's databases using data through the end of 2022, including:

- the Membership Database with patient-reported outcomes on over 9,700 affected individuals worldwide that also includes data from our annual Community Update Survey,
- the SMA Clinical Data Registry (CDR) containing electronic medical record (EMR) sourced data for over 800 patients receiving care from U.S.-based SMA Care Center Network sites, and
- the SMA Newborn Screening Registry (NBSR) with parent-reported outcomes for over 70 babies with SMA identified through statewide SMA newborn screening.

The 2022 State of SMA report presents a current snapshot of the quickly changing landscape of SMA. More specifically, the report includes age and gender breakdown of the SMA community, employment and education of adults affected with SMA, prevalence of SMA type and *SMN2* copy number, use of FDA approved treatments, impact of newborn screening, and decreasing mortality rates.

Highlights from the 2022 report include:

- Both children and adults are represented in Cure SMA databases. The average age was 22 years old, and at least 50% of individuals were 17 years or younger.
- Newborn screening has allowed for earlier diagnosis, regardless of *SMN2* copy number. Among the infants identified by newborn screening in 2022 (n=54), the reported average age of diagnosis confirmation was 0.4 months.
- Additionally, the time it takes to receive treatment after being diagnosed with SMA has been decreasing each year. For those diagnosed in 2022, the average time between diagnosis and treatment was less than one month (Figure 1).

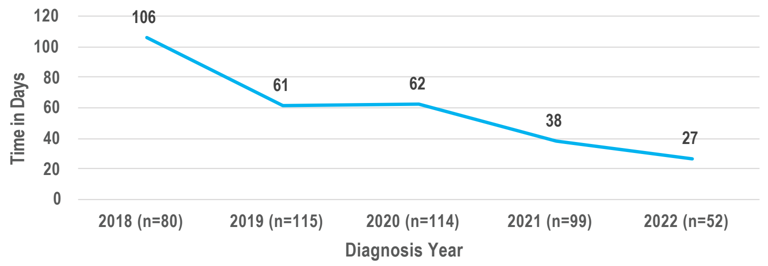


Figure 1. Average Time between Diagnosis and First FDA Approved Treatment, by Diagnosis Year

Cure SMA hopes data from this report will foster future research, programs, and development of additional therapies. Please scan the QR code below to access the 2022 State of SMA report.

CURE SMA INDUSTRY COLLABORATION

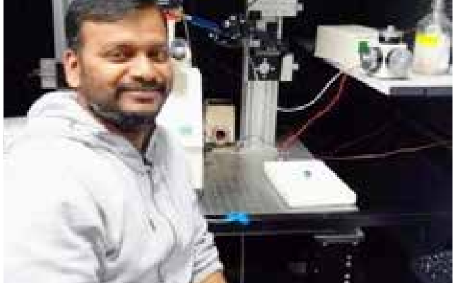
The Cure SMA Industry Collaboration was established in 2016 to leverage the experience, expertise, and resources of pharmaceutical, biotechnology companies, and other nonprofit organizations involved in the development of SMA therapeutics to more effectively address a range of scientific, clinical, and regulatory challenges. It is currently comprised of our partners at Biogen, Scholar Rock, Novartis Gene Therapies, Biohaven Pharmaceuticals, Epirium Bio, Genentech/Roche Pharmaceuticals, and SMA Europe.

Through the Industry Collaboration, we fund projects to ensure that effective, safe treatments can progress through clinical trials quickly and gain approval from the U.S. Food and Drug Administration (FDA) and international regulators. Our work also ensures that these treatments address the unmet needs of the SMA community, and that the community's priorities and goals are incorporated into the development, review, and approval of therapies.

During FY23 the Industry Collaboration refined treatment outcome measures for teens and adults, improved clinical trial site capacity, and enhanced knowledge of the SMA disease experience and the needs of affected individuals.

Additionally, we identified and addressed barriers that limit the SMA community's access to clinical research, treatment, and care. A summary of these accomplishments include:

- Publication of five research articles in peer-reviewed journals
- Hosting a Patient-Led Listening Session with the FDA to give members of the SMA community a forum to offer their perspectives on current and future SMA therapeutics
- Distribution of Cure SMA's 7th Annual Cure SMA Community Update Survey which captured 699 responses among 668 unique individuals
- Conducting focus group activities for affected adults and caregivers to identify barriers that limit access to research, treatment, and care in the SMA patient community
- Distribution of a survey, which captured 282 complete responses, to better understand our community's perspectives on treatment possibilities and tolerance for the side effects of currently available and planned therapies;
- Continued refinement of outcome measures for teens and adults (SMA-PRO, ATEND, SMACR-HI)
- Developing assessments for voice, speech, and swallow
- Conducting discussion groups to better understanding caregiver perspectives on patient-reported outcome (PRO) research instruments
- Distributing a survey to acquire comprehensive demographic information which captured 810 responses among 779 unique individuals


RESEARCH

CURE SMA HOSTS FDA LISTENING SESSION

On Thursday, August 4, 2022, six members of the SMA community spoke with the U.S. Food and Drug Administration (FDA) about their lived experiences with SMA and their unmet medical needs. This Patient-Led Listening Session was a private teleconference attended by patient advocates, FDA representatives from the Center for Drug Evaluation and Research (CDER) and the Center for Biologics Evaluation and Research (CBER), and representatives from Cure SMA.

The purpose of this listening session was to give members of the SMA community a forum to offer their perspectives on current and future SMA therapeutics. In recent years, progress in the SMA treatment landscape has been profound and rapid, resulting in FDA approval of three SMN-upregulating therapeutics. These treatments, together with the fact that nearly all newborns in the U.S. are now screened for SMA, have resulted in quickly evolving disease outcomes. However, significant unmet needs remain in those who are treated later in life, and other needs will arise in individuals who were treated early in life as they age.

CURE SMA LAUNCHES 7TH ANNUAL CURE SMA COMMUNITY UPDATE SURVEY

Since its initial launch in 2017, the Cure SMA Community Update Survey (CUS) has collected data and information on the SMA community's experiences and daily challenges. Our top priority is to represent the patient voice from the whole community, so we can drive research and care to meet patient needs. Data from the survey also informs Cure SMA's advocacy agenda and has been featured in legislative support statements, and educational outreach to federal and state leaders to showcase the priorities and needs of the SMA community related to newborn screening, employment, transportation, community living, and healthcare.

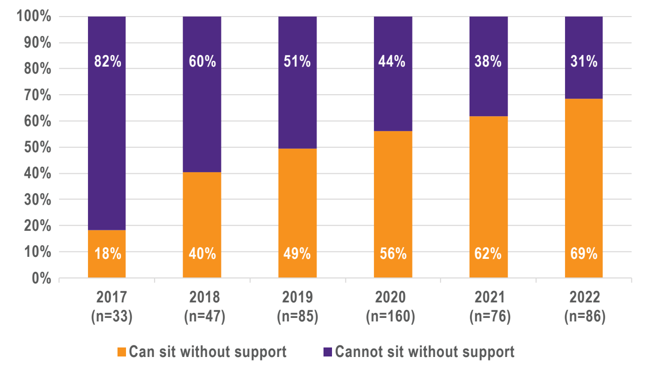


Figure 1. The proportion of individuals with 2 *SMN2* copies who report sitting without support has increased since 2017

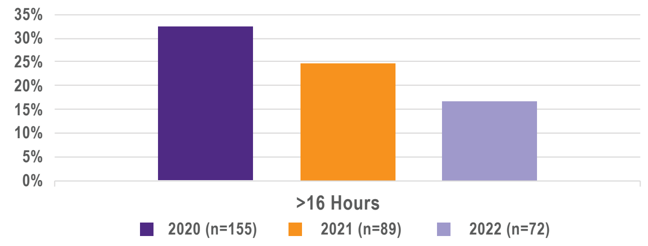


Figure 2. The proportion of individuals with 2 *SMN2* copies requiring 16 hours or more of breathing support has decreased from 2020 to 2022

Every piece of data collected allows Cure SMA to track changes in the attitudes, feelings, and actions of the SMA community over time. The survey covers questions on demographics, (e.g., sex, age at survey, vital status, educational level, employment); disease characteristics (e.g., age at diagnosis, *SMN2* gene copy number); respiratory interventions, motor function, surgeries and hospitalizations; and quality of life assessments. The aggregate data from the community responses have shown very exciting trends over time with improved SMA standards of care and increases in the use of disease modifying therapies. For example, among those with two *SMN2* copies (those with a severe SMA phenotype), there have been increasing motor function over time (Figure 2) and decreasing dependency on breathing support (Figure 3).

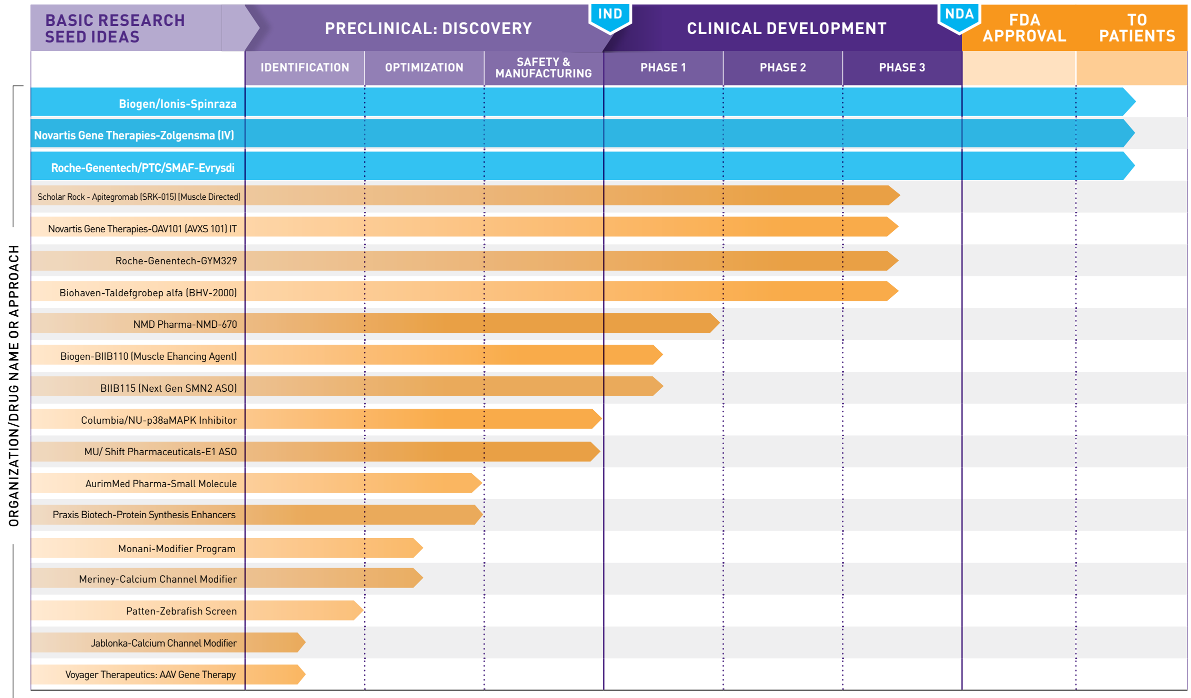
BASIC RESEARCH

Cure SMA is proud to have funded early-stage research for the three FDA approved drugs for SMA. While these treatments represent unprecedented advances for individuals with SMA, we know that there remains much to do and learn to ensure maximally effective treatments for every individual living with SMA.

As part of our continued investment in basic research, Cure SMA awarded 5 new basic research grants totaling $575,000 in early 2023. Thanks to the generosity of our community, we are pleased to be increasing our funding pool to $750,000 for the current grant cycle. Announcement of those awards will be made in early 2024.

SMA DRUG PIPELINE

We're funding and directing research with more breadth and depth than ever before. We know what we need to do to develop and deliver new therapies, which could also work in combination, to reach our goal of treatments for all ages and types. And we're on the verge of further breakthroughs that will continue to change the course of SMA, and eventually lead to a cure.



IND = Investigational New Drug **NDA** = New Drug Application Last updated: March 2023

BIOMARKER PUBLICATION

An important part of Cure SMA's core mission is to carry out and support research that will improve the quality of life for all people with SMA. We recently published a new research article, "Identifying Biomarkers of Spinal Muscular Atrophy for Further Development." This article appeared in the July 12, 2023 issue of the peer-reviewed research journal, the Journal of Neuromuscular Diseases.

FUNDRAISING

In the pursuit of groundbreaking treatments, therapies, and care, fundraising events and campaigns play a pivotal role in fueling our initiatives and propelling research forward. These events and campaigns not only serve as powerful mechanisms for generating financial support but also foster a sense of community and shared purpose. Join us in celebrating the success stories, milestones, and transformative outcomes made possible by the generosity and dedication of our supporters, foundations, and corporate partners. Each donation, participation, and advocacy effort contributes to the hope for a brighter future for those affected by SMA, driving us closer to our ultimate mission.

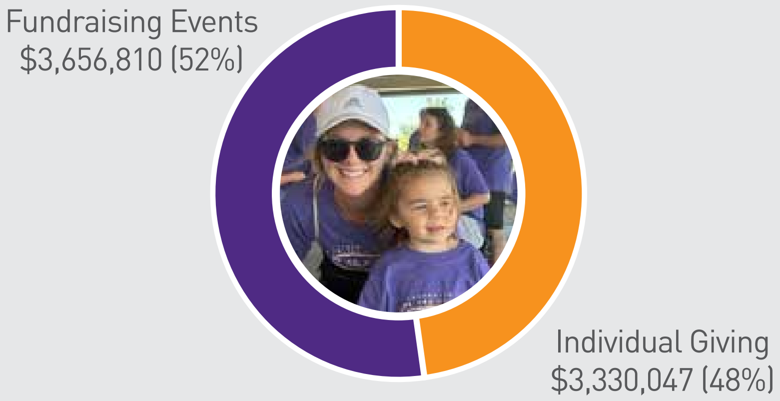
FY23 FUNDRAISING FINANCIALS

In Fiscal Year 2023, Cure SMA witnessed an incredible outpouring of support, with a remarkable $6,986,857 raised across more than 60 events and multiple giving campaigns. Beyond the impressive figures, these events represent moments where our community came together, fostering connection, unity, and shared purpose. Each event and campaign is a thread in the fabric of our mission, weaving stories of hope, resilience, and progress toward a cure for SMA. As we reflect on the diverse ways individuals contributed to this significant total, we celebrate not only the funds raised but also the profound impact of our shared commitment to one another.

$6,986,857

raised through Fundraising Events and Individual Giving

Individual Giving = $2,486,278
Workplace Giving = $127,267
Planned Giving = $342,835
Honors & Memorials = $373,667
Walk-n-Roll = $1,384,958
Distinguished Events = $1,639,137
Endurance = $163,322
Do-It-Your Way Fundraising = $469,392



ERIN TRAINOR MEMORIAL FUND

This past fiscal year, $295,000 was raised by our community, with a match of $295,000 for a total of $590,000 dedicated to the Care Center Network!

Care Centers guide our understanding of how SMA is changing and will improve how treatments and care are being delivered at the local level. We currently have 29 Care Centers across the U.S. with the goal to double that in the coming years.

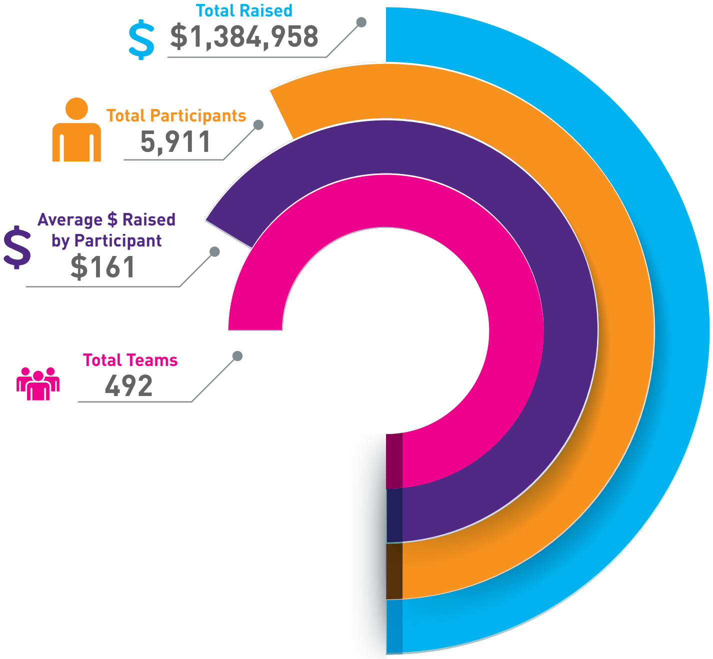
The Erin Trainor Memorial Fund was started by Barb and Gene Trainor in honor of their daughter, Erin, who was born with SMA Type 1 and would have turned 30 this year. Their generous support is helping transform the SMA landscape.

Cure SMA would like to thank Barb and Gene Trainor, the Erin Trainor Memorial Fund, and everyone who generously donated in support of the Care Center Network.

CURE SMA WALK-N-ROLL

In FY23, the Cure SMA Walk-n-Roll program raised an incredible $1,384,958 to support Cure SMA's funding of life-changing research, resources, and programming for those impacted by SMA. Nearly 6,000 people and 500 teams joined the movement, asked for support, and celebrated in 42 cities across the country.

Cure SMA thanks everyone who participated this year for coming together in your communities, bringing awareness to SMA, and raising vital funds needed to continue funding breakthroughs in research, care, and support!



TO ALL OUR CHAPTER LEADERS AND VOLUNTEERS

Thank You



CORPORATE PARTNERS, FOUNDATIONS, & SPONSORS

Cure SMA extends heartfelt gratitude to our esteemed event corporate sponsors and foundations whose unwavering support has been instrumental in advancing our mission throughout Fiscal Year 2023. Your commitment to partnering with us has propelled critical research, expanded access to care, and strengthened the foundation of support for individuals and families affected by SMA. Your generosity not only fuels innovation but also serves as a beacon of hope for a brighter future. Together, we are making significant strides toward a world where every person living with SMA can lead independent and fulfilling lives. Thank you for standing with us and for being catalysts of change in the pursuit of a cure.

Sean Adams
Aegon Transamerica Foundation
Albert H Hopper Monuments Inc.
Alight Solutions LLC
Anvil Iron Works Inc
Argentic Management
Assured Partners
BAYADA Pediatrics
Berman Indictor LLP
Biogen
Courtney Black
BMI Mechanical Inc
Boardman & Clark LLP
BraunAbility
BRE Inc.
Busick Insulated Glass
Business Furniture + Co
Capital Group
Children's of Alabama
Cigna Health and Life Insurance Company
Cintas Corporation
Cohn Reznick
Colliver Insurance
Compass Construction Foundation
Concentus Wealth Advisors
Copper Moon Coffee
Coyle Auto Group
CRB
CTIA
DAC, LLC
Daniel Dekemper
Mary and David Dilenschneider
DiMella Shaffer Architects
Epirium Bio
Ernst & Young US LLP
Falasca Mechanical, Inc
Fifth Generation, Inc
Fifth Third Bank
Lorraine and William Finelli
Finishing Touch Team LLC
Morgan Fischer
Genentech
Gorman and Bunch Orthodontics
Green Mare Labs, LLC
Gutwein Family Giving Fund
Yvonne Gutwein
Haynes Construction Co
Stacy and Jeff Hiatt
Hyatt Agency
Indy Pro Inspection Service Inc
Innova Services Corporation
Inside & Outside Home Improvement
Inside Out Home Services
ISPE
JDB Plumbing & Heating, Inc
Jewish Federation of Cincinnati
Johnson & Johnson
JP Morgan Chase
Knepp Financial Group
Land Services USA Inc

Larson Family Chiropractic Inc

Law Office of Luke Reynoso, PLLC

Lenex Steel Company

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Millennium Respiratory Services

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Debbie and Pat O'Neil

Over The Mountain Glass Inc

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Parkside Animal Hospital

Permobil Foundation

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Pingrong Xue CPA

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Quest Diagnostics

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Rake Law Group PC

Reach Climbing & Fitness

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Rutherford PBA Local 300

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Steve Brill

Steve Stricker American Family Insurance Foundation

Paul Swibinski

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The PromptCare Companies Inc

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Thriven Design

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Waters, McPherson, McNeill PC

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White Home Products

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Samuel Pfaff, PhD – Investigator of the Howard Hughes Medical Institute and Professor at the Gene Expression Laboratory at the Salk Institute for Biological Studies in La Jolla, California; Motor Neuron Biologist

FINANCIAL BREAKDOWN

STATEMENT OF FINANCIAL POSITION

FOR THE YEAR ENDED JUNE 30, 2023 AND 2022

ASSETS	2023	2022
Cash, cash equivalents, and investments	$6,454,699	$6,855,851
Receivables and other assets	5,873,747	4,067,709
Fixed assets, net	384,858	373,899
Total Assets	***$12,713,304***	***$11,297,459***

LIABILITIES	2023	2022
Accounts payable and accrued expenses	$4,195,716	$2,021,267
Research and grants payable	1,724,857	2,045,472
Total Liabilities	5,920,573	4,066,739

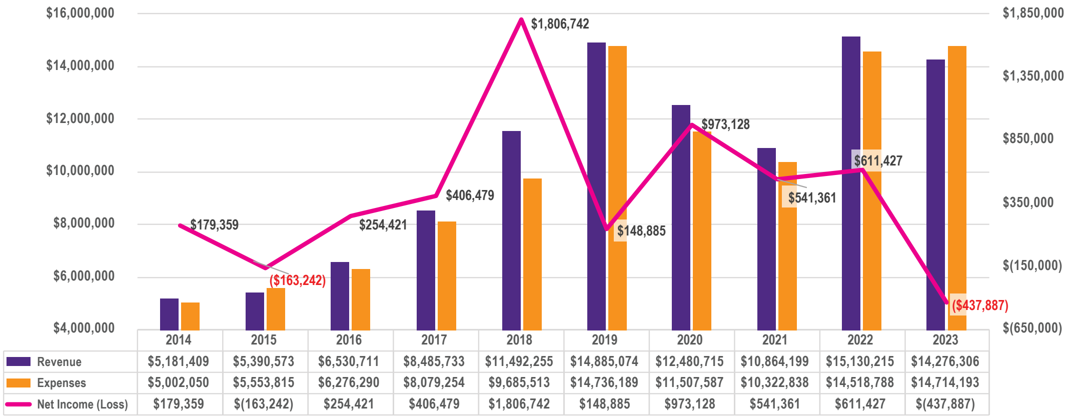
NET ASSETS	2023	2022
Unrestricted	$1,566,462	$3,294,012
Temporarily restricted	3,301,558	2,327,339
Permanently restricted	1,924,711	1,609,369
Total Net Assets	6,792,731	7,230,720
Total Liabilities and Net Assets	***$12,713,304***	***$11,297,459***

STATEMENT OF ACTIVITIES

FOR THE YEAR ENDED JUNE 30, 2023 AND 2022

SUPPORT AND REVENUE	2023	2022
Contributions:		
Contributions and grants	$6,378,572	$8,197,505
Special events, net	3,266,484	2,153,368
Program revenue	3,981,929	3,528,616
Other revenue	258,614	915,428
Total Revenue	13,885,599	14,794,917

EXPENSES	2023	2022
Program Services		
Research	$3,723,718	$5,185,859
Patient services	2,595,626	2,805,278
Community support	4,534,772	2,661,871
Awareness	669,641	706,855
Total program services	11,523,757	11,359,863
Supporting services		
Management & general	1,586,641	904,581
Fundraising	1,213,190	1,919,044
Total supporting services	2,799,831	2,823,625
Total Expenses	14,323,588	14,183,488
Increase (decrease) in net assets	***($437,989)***	***$611,429***



	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Revenue	$5,181,409	$5,390,573	$6,530,711	$8,485,733	$11,492,255	$14,885,074	$12,480,715	$10,864,199	$15,130,215	$14,276,306
Expenses	$5,002,050	$5,553,815	$6,276,290	$8,079,254	$9,685,513	$14,736,189	$11,507,587	$10,322,838	$14,518,788	$14,714,193
Net Income (Loss)	$179,359	$(163,242)	$254,421	$406,479	$1,806,742	$148,885	$973,128	$541,361	$611,427	$(437,887)

Variation between financials and the chart due to the deduction of "Benefit to Donor"

Financial information presented has been summarized from financial statements audited by Warady & Davis LLP dated June 30, 2023 and 2022.

WHERE YOUR CONTRIBUTIONS GO

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.

RESEARCH **26%**

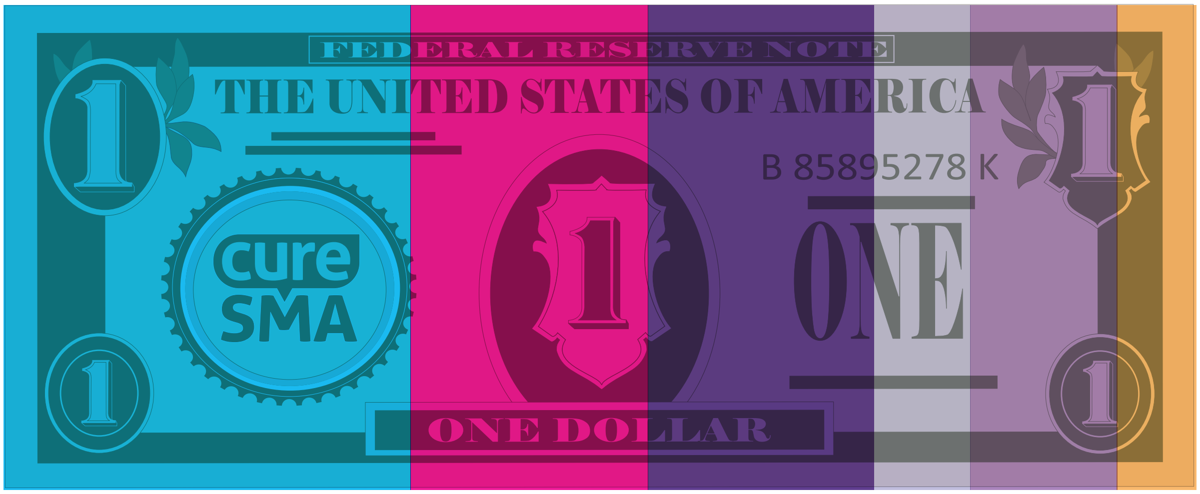
Basic research to investigate the biology and cause of SMA to identify the most effective strategies for drug discovery.

PATIENT SERVICES **18%**

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

MANAGEMENT & GENERAL **11%**

Cure SMA operations.



COMMUNITY SUPPORT **32%**

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 **5%**

To advocate for critical policies and initiatives to make daily life better for people with SMA.

FUNDRAISING **8%**

To plan, oversee, and execute campaigns and events that raise critical funds for Cure SMA and the SMA community.

Note: The figures above are taken from the 2023 fiscal year. Our complete financial information can be found at [*www.curesma.org/annual-reports-financials/.*](www.curesma.org/annual-reports-financials/)

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