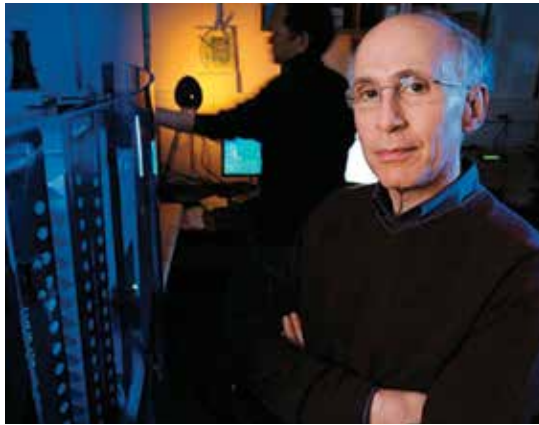




# 2022 ANNUAL REPORT







## Dear SMA Community,

Cure SMA's Annual Report serves as a look back at the progress we have made through your generous support, while also recognizing how much we have yet to do to improve the daily lives of everyone impacted by SMA and reach our ultimate goal of a cure.

2022 was an active and exciting year for Cure SMA and our SMA community! Our 2022 Annual SMA Conference was held in-person for the first time in nearly three years and was incredibly well received by both Community and Research & Clinical Care attendees. We were also back and better than ever with our local in-person Walk-n-Roll and Summit of Strength programs, hosting more than 300 events. The Annual Conference, Walk-n-Roll, and Summit of Strength events demonstrated a clear desire from many members of our community to come back together for a collective experience.

In addition to our exciting in-person events, we made major strides in several other key areas. We now have three powerful SMA treatments with close to three quarters of affected individuals in the U.S. on at least one of those treatments, and many individuals utilizing a combination of SMN and non-SMN treatments. We also have newborn screening across 98% of the U.S. and more clinical trials happening than ever before.

Throughout 2022 and now into 2023, Cure SMA also focused on key partnerships and campaigns including significant matched donation programs through the Erin Trainor Memorial Fund for our Care Center Network and with Richard and Jane Nunemaker for Basic Research, along with many clinical trial updates and webinars with our pharmaceutical partners.

Speaking of basic research, we brought back our basic research funding, focusing on research to discover new non-SMN therapies and combination treatment approaches. Our goal is to gain the knowledge and understanding to restore strength and function. We aim to triple our investment in basic research in the coming years.

As we look toward the future with research, it is just as important that we also focus on the very real needs of the SMA community now, which include access to high quality care. We grew our Care Center Network to 30 active Care Centers across the U.S. We are halfway to our goal of 60 Care Centers.

Finally, in addition to research, treatment, and care, we are addressing opportunities to improve the daily lives of all 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 successes you will see highlighted in this report are a direct result of the hard work and dedication of our entire community—individuals with SMA, their families, clinicians, researchers, industry, and donors. Thank you for all you do, as we would not be where we are today without you and your continued support.

Best,



Kenneth Hobby  
President



Nick Farrell  
Chairman of the Board



# NATIONAL SUPPORT

## Nationwide Programs Offer Support for Families Affected by SMA

Each year, Cure SMA provides families affected by SMA with resources to help them live active, engaged, and hopeful 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** 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, sent automatically and filled with toys and helpful items that have been recommended by other SMA parents.
- **Support packages** available upon request for teens and adults with SMA that includes 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.

## What We've Achieved Together In 2022



**2,377**  
FAMILY SUPPORT  
ITEMS SENT



**662** NEWLY  
DIAGNOSED FAMILIES  
REACHED



**2,200+** PARTICIPANTS  
AT WALK-N-ROLL EVENTS



**2,400** FAMILIES &  
RESEARCHERS AT ANNUAL  
SMA CONFERENCE



**46 STATES** TAKING ACTION  
IN NEWBORN SCREENING  
INITIATIVE



**28 CARE CENTERS**  
IN THE SMA CARE  
CENTER NETWORK



**\$5 MILLION** INVESTED  
IN RESEARCH



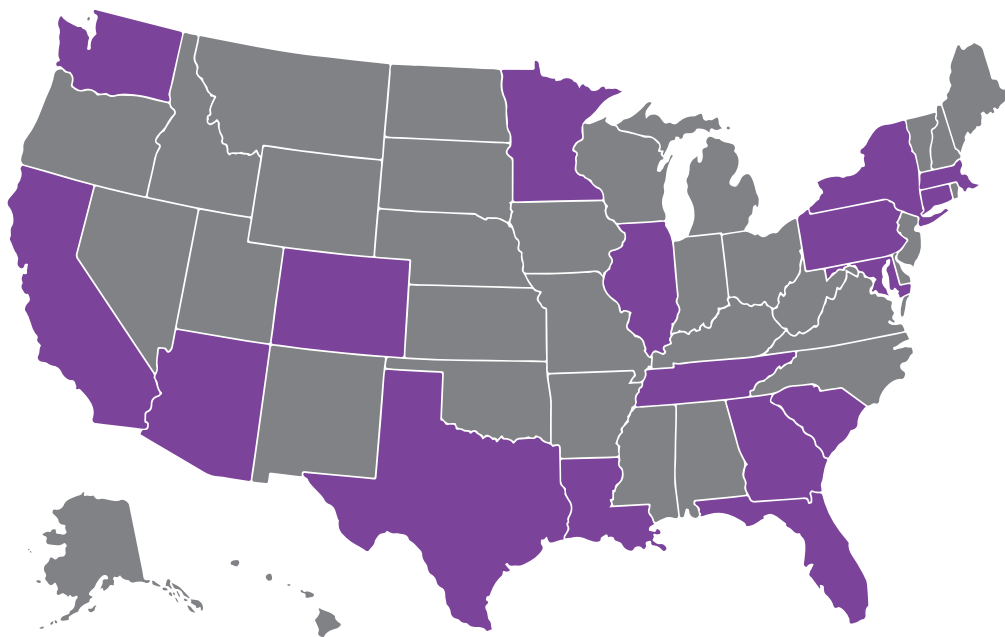
**20** SUMMIT OF STRENGTH  
LOCAL EVENTS NATIONWIDE



**22 DRUG PROGRAMS**  
CURRENTLY IN  
PROGRESS

## Local Events Fosters Greater Connections in SMA Community

A young man with short dark hair, wearing a dark jacket, is shown in profile, speaking into a silver microphone. He is holding the microphone with his right hand. The background is dark and out of focus, suggesting an indoor setting like a stage or a large hall.



Atlanta, GA  
Orlando, FL  
Seattle, WA  
Nashville, TN  
Charleston, SC  
Denver, CO  
Boston, MA

Hartford, CT  
Miami, FL  
Anaheim, CA  
New Orleans, LA  
San Antonio, TX

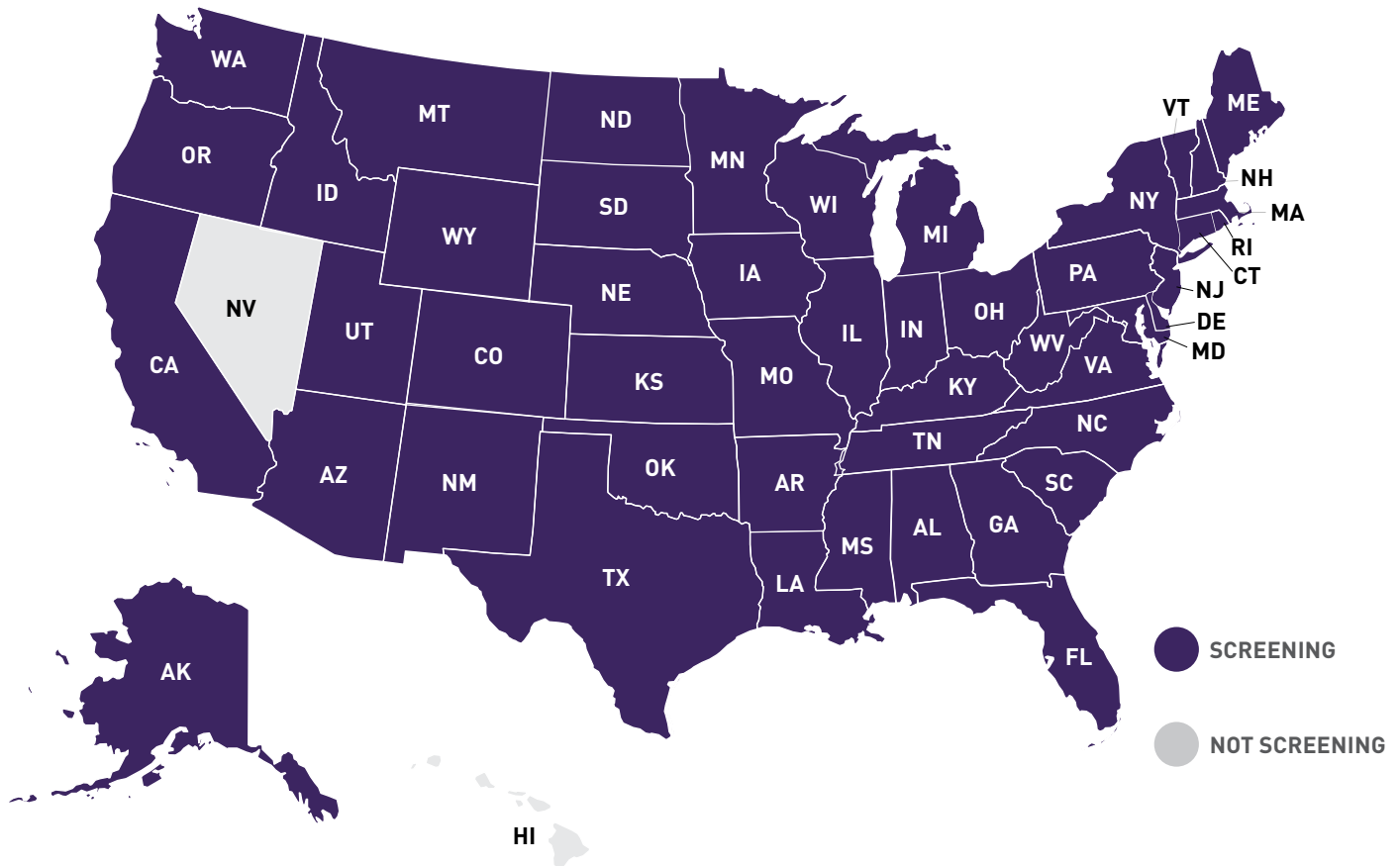
# ADVOCACY

## Newborn Screening of SMA Inches Closer to 100%

Four years into the federal recommendation that states screen newborns for SMA, 47 states now screen for the condition, covering 97 percent of all babies born in the U.S. During fiscal year 2022 alone, 9 states began screening for SMA, and 2 states transitioned from statewide pilots to permanent newborn screening programs. Individuals with SMA, their families, and other Cure SMA supporters and partners have been instrumental in educating decisionmakers about the importance of an early diagnosis through newborn screening in saving lives and improving developmental outcomes. Cure SMA remains active in assisting the remaining non-screening states.

### STATES SCREENING & NOT SCREENING FOR SMA

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



#### NEWBORN SCREENING OF SMA (FY 2022)

##### Implemented

- Alabama
- Alaska
- Arizona
- Louisiana
- New Jersey
- New Mexico

##### Pilot to Permanent Program Transition

- Iowa
- North Dakota

# ADVOCACY

## Educating Congress About Issues Impacting the SMA Community

Individuals with SMA and their families ranked health care, transportation, employment & financial security, housing, technology, education, and disability rights as their top advocacy priorities. Cure SMA launched a new online advocacy tool to make it easier for individuals with SMA, their families, and other advocates to educate Congress about these SMA priorities. During the 2022 Cure SMA conference, a record number of advocates sent messages to their Members of Congress through this new advocacy system in support of accessible transportation, SMA research, and caregiving supports. In addition, Cure SMA reached out to every U.S. Senator and U.S. Representative to update them on the current state of SMA, including recent progress and additional unmet needs. Cure SMA also hosted Members of Congress at its Hope on the Hill Washington, D.C. event to recognize policymakers for their role in the progress in SMA. The SMA community's year-long advocacy efforts were successful in increasing awareness about the SMA and the community's goals around breaking down barriers and increasing independence.





# CONFERENCE

## Annual SMA Conference Attendance Continues to Grow and Offer Value to Community

Cure SMA's Annual SMA Conference is the largest SMA conference in the world, bringing together researchers, healthcare professionals, and families to network, learn, and collaborate. It is the centerpiece of our national support program. The 2019 Annual SMA Conference at the Disneyland Hotel in Anaheim, Calif, was an impactful weekend filled with community, research, care, and—most importantly—fun for the more than 2,400 attendees – our largest conference to date!

The 4-day weekend included a variety of workshops, research discussions, and specials events for all attendees – children, teens, and adults. The Conference began on Friday 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 family workshops and 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, and the newly-established “Adults with SMA Lounge” that provided a space for adults with SMA to mingle and relax.



## 2023 ANNUAL SMA CONFERENCE



THURSDAY, JUNE 29TH – SUNDAY, JULY 2ND

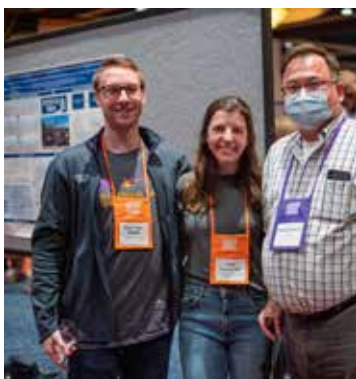
Disney's Yacht & Beach Club Resort in Orlando, Florida

## Cure SMA Research and Clinical Care Meeting

The SMA Research and 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 2022 Cure SMA Research and Clinical Care Meeting was held June 15-17, 2022 at Disneyland with 462 attendees. Sessions included: Clinical Care with discussion of ethics, SMA newborn screening, and SMA nutrition and offered 5.5 credit hours of CME/CE; a special session titled “Reverse Translation: How do real world observation inform the most pressing basic research questions?”, Basic Research; Clinical Research, Clinical Drug Development; and poster sessions.

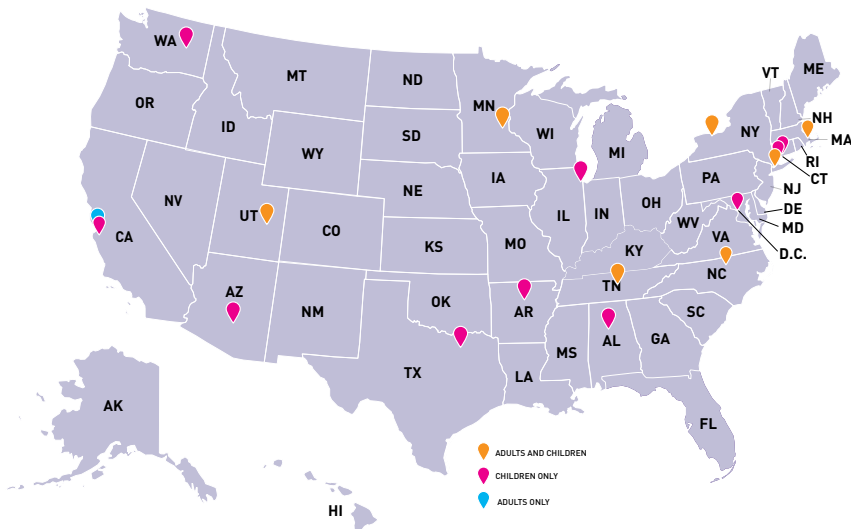


# CONFERENCE



# CLINICAL CARE

## Cure SMA Care Center Network and SMA Clinical Data Registry Continues to Expand



Advocate Children's Hospital, Park Ridge, IL  
Arkansas Children's Hospital, Little Rock, AR  
Boston Children's Hospital, Boston, MA  
Children's of Alabama, Birmingham, AL  
Children's National Medical Center, Washington, DC  
Columbia University, New York, NY  
Connecticut Children's Medical Center, Hartford, CT  
Duke University Medical Center, Durham, NC  
Gillette Children's Specialty Healthcare, St. Paul, MN  
Phoenix Children's Hospital, Phoenix, AZ  
Stanford Health, Palo Alto, CA  
Stanford Children's Health, Palo Alto, CA  
Seattle Children's Hospital, Seattle, WA  
University of Rochester Medical Center, Rochester, NY  
The University of Utah, Program for Inherited Neuromuscular Disorders, SLC, UT  
University of Texas Southwestern/Children's Health, Dallas, TX  
Vanderbilt University Medical Center, Nashville, TN  
Yale Pediatric Neuromuscular Clinic, New Haven, CT

Our primary focus is supporting care of the highest value to individuals with SMA. As a result of FDA approved treatments and successful initiatives, such as the Cure SMA Care Center Network and SMA Clinical Data Registry, we have made significant progress enhancing the lives of people impacted by SMA in our community.

The care for people with SMA is more important than ever to ensure timely access to new treatments and optimized outcomes. Our goal is to ensure that the diversity of centers in the Care Center Network provides real-world data that best represents the SMA community.

The Cure SMA Care Center Network has expanded to 28 partners, as of June 2022. These Centers across the country represent pediatric and adult care centers, provide multidisciplinary care, and contribute consented SMA patient data electronically to the SMA Clinical Data Registry. This real-world data will lead to the creation of evidence-based guidelines for care, better characterization of the changing SMA phenotype, and move care and new treatments forward. As we move forward, we seek to expand the network to include 50-60 sites.

*The growth of the Cure SMA Care Center Network and SMA Clinical Data Registry is supported in part by the Cure SMA Real-World Evidence Collaboration. The Cure SMA Real World Evidence Collaboration was established in 2021 to leverage the experience, expertise and resources of pharmaceutical and biotechnology companies and nonprofit organizations involved in development of SMA therapeutics to guide the future direction of real world data collection and use in SMA. Funding for this project was provided by the Cure SMA Real World Evidence Collaboration; members include Cure SMA, Biogen, Genentech/Roche Pharmaceuticals, Novartis Gene Therapies, and SMA Europe. In addition, we acknowledge the Oscar G. and Elsa S. Mayer Family Foundation and an endowment from Bill and Susan Orr and the Tyler William Orr Memorial Fund for their support. We thank the SMA community for support and participation in the SMA Clinical Data Registry. We thank the Care Center Network for their commitment and contributions.*



# CLINICAL CARE



The mission of the Cure SMA Care Center Network is to provide the best care—including offering new therapies—as well as gather and disseminate new knowledge to advance the SMA standard of care for pediatric and adult persons with SMA.

## Goals of the Cure SMA Care Center Network

- Improve SMA clinical care and disease management, leading to creation of evidence to support a robust standard of care for SMA.
- Standardize care across the U.S. to improve healthcare delivery, decrease healthcare costs and burden of disease, improve the patient experience, and facilitate more rapid therapeutic development.
- Develop clinical care center capacity to deliver new therapies to individuals with SMA and increase patient access to new treatments.
- Increase the number of sites for SMA clinical trials.
- Provide a resource for local patient services and family support and regional healthcare providers.

## State of SMA

Cure SMA launched its first annual State of SMA report in May 2022. The purpose of this report is to share highlights from Cure SMA's three databases: the membership database with patient reported outcomes on over 9700 affected individuals worldwide that also includes data from our annual community update survey, the SMA clinical data registry (CDR) that contains electronic medical record (EMR) data sourced from 19 US-based SMA Care Center Network sites; and the SMA newborn screening registry with data from parents of babies with SMA identified through statewide SMA newborn screening.

In addition, this snapshot of the quickly changing landscape of SMA 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. This report documents the 2021 state of SMA and is intended to foster future research, programs and development of additional therapies.



*Cure SMA is thankful for all the members of the SMA community who have generously shared their data to make this report possible. Cure SMA also thanks the Care Center Network for their care of patients with SMA and work with the CDR. Additionally, we're grateful for the support and funding provided by the Cure SMA Industry Collaboration (SMA-IC), the Cure SMA Real World Evidence Collaboration (RWEC), and the Cure SMA Newborn Screening Coalition (NBSC).*



# CLINICAL CARE



## The Cure SMA Industry Collaboration

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

Pharmaceuticals, Epirium Bio, and SMA Europe. Additionally, the work of the Collaboration is supported by funds provided by Biogen, Genentech/Roche, Scholar Rock, Novartis Gene Therapies, Biohaven Pharmaceuticals, and Epirium Bio.

## Real World Evidence: Cure SMA Care Center Network and Clinical Data Registry

The Cure SMA Real World Evidence Collaboration (RWEC) was established in 2021 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. Members of the RWEC include Biogen, Novartis Gene Therapies, Genentech/Roche, and SMA Europe.

## The Cure SMA Newborn Screening Coalition

The Cure SMA Newborn Screening Coalition (NBSC) was established in 2017 to leverage the experience, expertise and resources of pharmaceutical and biotechnology companies and nonprofit organizations involved in the development of SMA therapeutics to advance newborn screening for SMA. Members of the NBSC include Novartis Gene Therapies, Genentech/Roche, and Biogen.

## Cure SMA Care Center Network

Cure SMA has partnered with 19 SMA Care Centers across the US who provide multidisciplinary care for people with SMA. These centers are committed to establishing and implementing an evidence-based standard of care for SMA through a centralized registry collection of SMA care and treatment real world data. Consented patient electronic medical record (EMR) data is electronically transferred from the Care Center to the SMA Clinical Data Registry (CDR).

# RESEARCH

## Cure SMA Continues to Advance a Comprehensive Research Program, Science Education

Over our past fiscal year—from July 1, 2021, to June 30, 2022—Cure SMA has funded over \$7.3 million in new and ongoing research funding. This funding will be used strategically to help accelerate research, and ensure we are developing treatments for all types, ages, and stages of SMA. The areas funded include:

- Basic research, with a particular focus on funding approaches to develop combination therapies.
- Drug discovery, to convert basic research ideas into practical new drug candidates.
- Clinical and regulatory research, to facilitate clinical trials for all types and stages of SMA, and to guide safe and effective drug candidates toward regulatory approval.
- Pediatric Neuromuscular Clinical Research Network (PNCN), to collect highly curated data on patients with SMA, to conduct clinical trials, to explore, develop and test new outcome measures.
- Real World Evidence: Cure SMA Care Center Network and Clinical Data Registry, to gather clinical data that leads to evidence based clinical guidelines and standards of care.
- 26th Annual SMA Research and Clinical Care Meeting, to bring together the leading SMA scientists, clinicians, and drug developers to develop SMA research strategies.



If you missed any of our funding announcements, catch up on them in our news section at [www.cureSMA.org/news](http://www.cureSMA.org/news). Each announcement includes a profile of the researcher who is receiving the grant and explains more about their projects and how they might benefit the SMA community.

## Clinical and Regulatory Research

**\$1.8M in funding in FY22**

As more SMA drug programs progress through clinical trials, there is an increasing need for us to address clinical and regulatory issues and bring the patient voice into the process. In 2016-2017, we launched the SMA Industry Collaboration (SMA-IC), a group of pharmaceutical and biotechnology companies in SMA drug development that work together on these projects to benefit our community. Funding for this area will be directed toward several critical projects:

- Increasing clinical trial site capacity and optimizing readiness by providing tools that would enhance sites' ability to conduct effective clinical trials in SMA.
- Regulatory issues in SMA drug development including,
  - Assessing the feasibility of combination therapies in pre-clinical and clinical trials
  - [Scientific-Considerations for Drug CombinationsBooklet](#)
  - Developing adult outcome measures for clinical trial use.
  - Obtaining a Critical Path Innovation Meeting with the FDA.
- Conducting the Annual SMA Community Survey.
- Collecting data in the SMA Newborn Screening Registry to better understand the impact of SMA newborn screening on SMA.
- Identifying disparities and perceived gaps in SMA care, treatment, and clinical trial research access.

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# RESEARCH

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## Pediatric Neuromuscular Clinical Research Network (PNCR)

\$1.5M in funding in FY22

### Pediatric Neuromuscular Clinical Research Network

- Boston Children's Hospital, Children's Hospital of Philadelphia, Columbia University Irving Medical Center, Stanford University, data coordinating center at University of Rochester.
- Large natural history study on over 500 patients used as benchmark for drug approvals.
- Developed key outcome measure used globally in SMA trials
- Designed and participated in all major drug trials in SMA.

### Projects funded by Cure SMA

- Natural history data collection
- Columbia SMA Biorepository
- PT Education, Wearable Technology, & Muscle Fatigue/ Dysfunction
- Tracking of SMA Patients identified by Newborn Screening
- Longitudinal Evaluation of Adults with SMA
- Developing New and Refining Existing Outcome Measures, i.e., ATEND, bulbar function, etc.
- Participation in the Cure SMA Care Center Network.

## Real World Evidence: Cure SMA Care Center Network and Clinical Data Registry

\$1.3M in SMA Care Center Network grants in FY22

In FY22, the Care Center Network expanded to 28 Care Centers and 17 were integrated with the Cure SMA Clinical Data Registry collecting patient data to establish an evidence-based standard of care. Seven new Care Centers were added this year.

## Cure SMA Research and Clinical Care Meeting

The 2022 Cure SMA Research and Clinical Care Meeting was held June 15-17, 2022 at Disneyland with 462 attendees joining over the 3 days. Sessions included: Clinical Care CME which offered 5.5 credit hours of CME/CE, Basic and Clinical Research, and Clinical Drug Development.

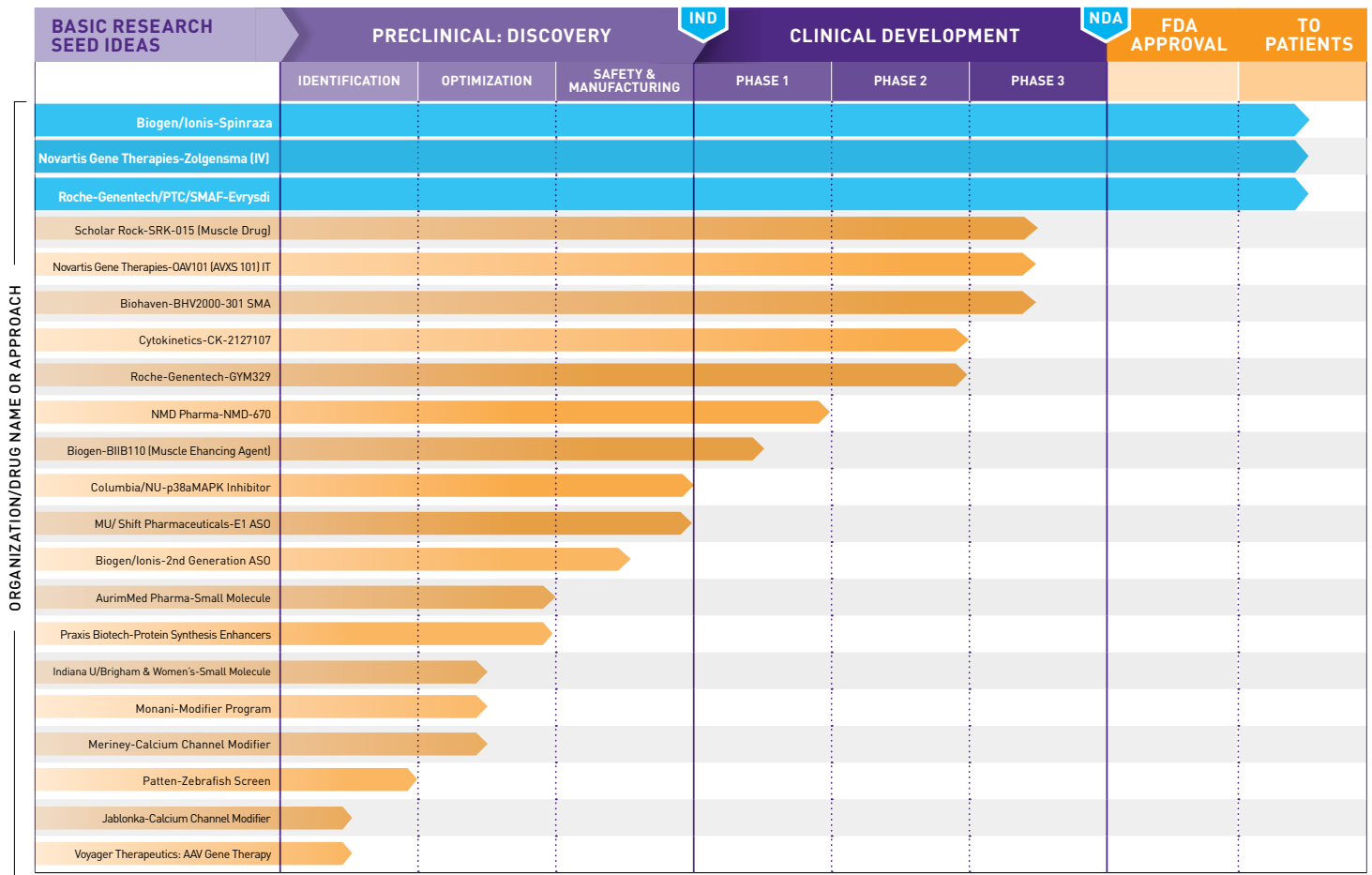


# RESEARCH

## Cure SMA Drug Pipeline

Cure SMA has directed and invested in comprehensive research that has shaped the scientific community's understanding of SMA, led to breakthroughs in treatment and care, and provided individuals and families the support they need today.

**As our thinking around treatment needs for SMA evolves, new research strategies will lead to symptomatic and muscle-targeting therapies that will work in combination with approved disease-modifying genetic treatments.**



**IND** = Investigational New Drug

**NDA** = New Drug Application

Last updated: June 2022

The SMA Drug Pipeline reflects the SMA community's progress in gaining access to Evrysdi, Spinraza, and Zolgensma, as well as the progress of additional research programs currently in development. We continue to identify and explore four possible treatment targets:

1. Replacement or correction of the faulty SMN1 gene.
2. Modulation of the low functioning SMN2 "back-up gene."
3. Neuroprotection of the motor neurons affected by loss of SMN protein.
4. Muscle protection to prevent or restore the loss of muscle function in SMA.

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# BOARD, COMMITTEE, AND ADVISORY MEMBERS

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Shannon Zerzan

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Jay Chung – Committee Member

Kaleen Robinson – Committee Member

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# BOARD, COMMITTEE, AND ADVISORY MEMBERS

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Fred W. Troutman, PhD, RN  
Laura Watne, MS, RD, CSP



# FINANCIAL BREAKDOWN

## STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED JUNE 30, 2022 AND 2021

ASSETS	2022	2021
Cash, cash equivalents, and investments	\$6,855,851	\$8,294,066
Receivables and other assets	3,968,146	1,138,834
Fixed assets, net	373,899	533,538
Other assets	99,563	245,876
<b>Total Assets</b>	<b>\$11,297,459</b>	<b>\$10,212,314</b>

LIABILITIES	2022	2021
Accounts payable and accrued expenses	\$2,021,267	\$1,528,335
Research and grants payable	2,045,472	2,064,687
<b>Total Liabilities</b>	<b>4,066,739</b>	<b>3,593,022</b>

NET ASSETS	2022	2021
Unrestricted	\$3,294,012	\$1,805,369
Temporarily restricted	2,327,339	3,342,289
Permanently restricted	1,609,369	1,471,634
<b>Total Net Assets</b>	<b>7,230,720</b>	<b>6,619,292</b>

<b>Total Liabilities and Net Assets</b>	<b>\$11,297,459</b>	<b>\$10,212,314</b>
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## STATEMENT OF ACTIVITIES FOR THE YEAR ENDED JUNE 30, 2022 AND 2021

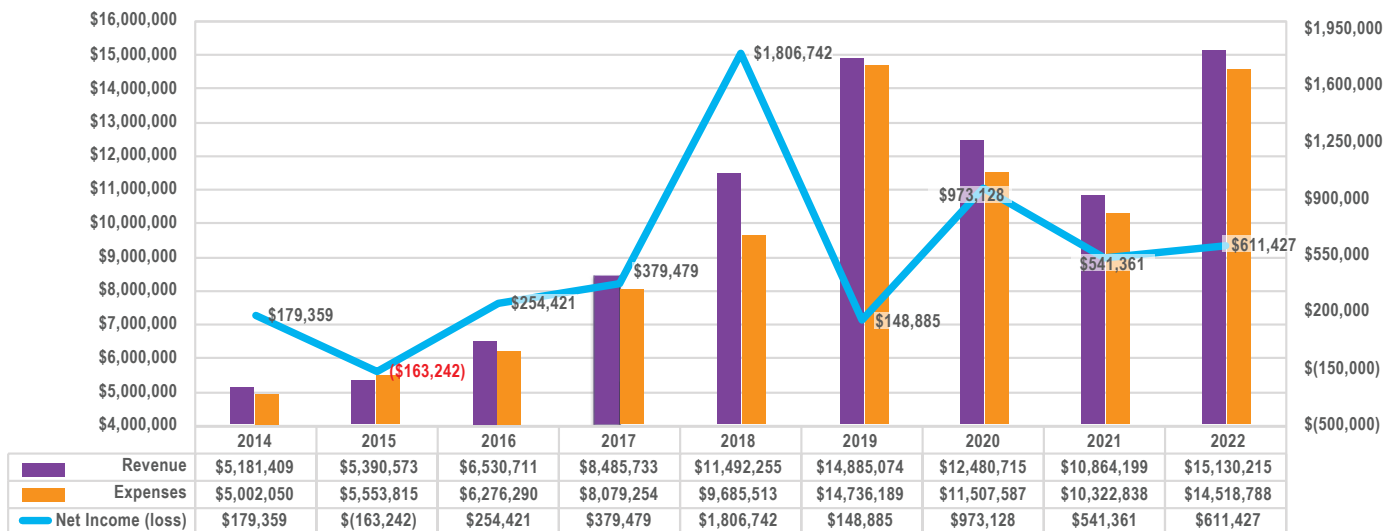
SUPPORT AND REVENUE	2022	2021
Contributions:		
Contributions and grants	\$7,501,012	\$5,539,538
Special events, net	2,849,860	2,425,902
Program revenue	3,528,616	1,627,325
Other revenue	915,428	1,200,332
<b>Total Revenue</b>	<b>14,794,916</b>	<b>10,793,097</b>

EXPENSES	2022	2021
Research	\$5,185,859	\$3,333,479
Patient services	2,805,278	2,050,709
Community support	2,661,871	1,863,070
Awareness	706,855	525,452
Management & general	904,581	658,317
Fundraising	1,919,044	1,820,735
<b>Total Expenses</b>	<b>14,183,488</b>	<b>10,251,735</b>

<b>Change in Net Assets from Operations</b>	<b>\$611,428</b>	<b>\$541,362</b>
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Financial information presented has been summarized from financial statements audited by Warady & Davis LLP dated June 30, 2022 and 2021.

## REVENUE & EXPENSE



# 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. Every dollar goes to...

## RESEARCH 37%

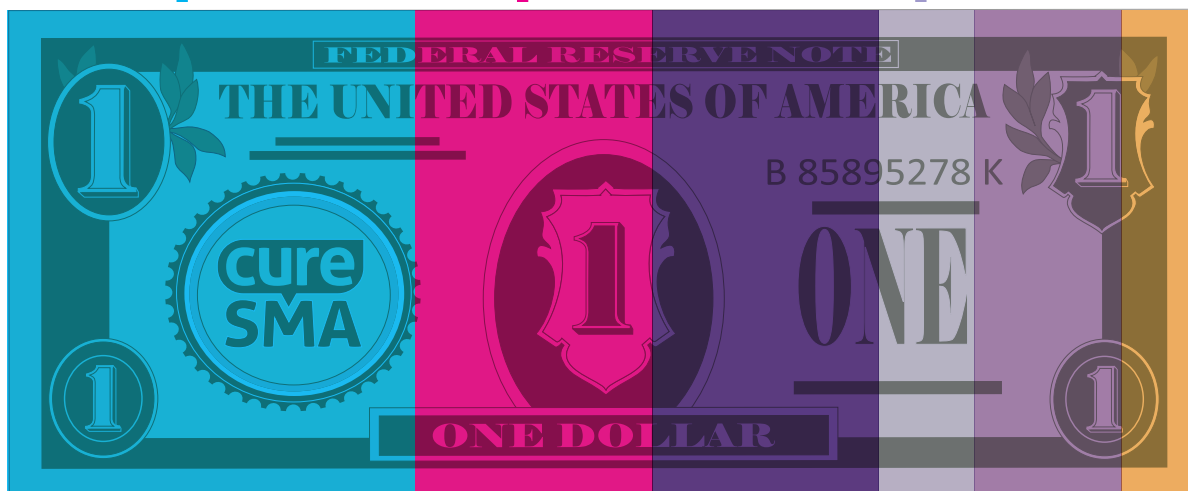
Basic research to investigate the biology and cause of SMA to identify the most effective strategies for drug discovery.

## PATIENT SERVICES 20%

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 6%

Cure SMA operations.



## 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 5%

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

## FUNDRAISING 14%

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 2022 fiscal year. Our complete financial information can be found at [www.curesma.org/annual-reports-financials/](http://www.curesma.org/annual-reports-financials/).



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