



# IN UNITY. TOWARD PROGRESS.

SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.

**2023-2024**

**Impact Report**

# IN UNITY. TOWARD PROGRESS.

It is with great pride and gratitude that I share with you the Sickle Cell Disease Association of America, Inc. (SCDAA) Impact Report. This report outlines the work that SCDAA has accomplished between June 2023 and July 2024 on behalf of the individuals and families impacted by sickle cell disease. The pages that follow illuminate the collective efforts and triumphs of those who work together — sickle cell warriors, caregivers, community-based organizations, sponsors, supporters, medical providers and researchers — to improve the quality of life for everyone affected by this disease.

2023 marked a significant milestone at SCDAA, as we celebrated the 51st year since our organization's founding. Our journey over the last five decades has been marked by resilience, advocacy and a steadfast commitment to creating a brighter future for those battling this challenging condition.

Our Impact Report shares stories of courage, innovation and hope. From the individuals whose lives have been transformed by our programs to the dedicated researchers pushing the boundaries of knowledge, the progress we have made is a testament to the power of collective action and the impact we can have when we unite under a common cause.

Our community is at the heart of everything we do. It is your support, dedication and belief in our mission that fuels our efforts. As we share our achievements, we also recognize the challenges that persist. The fight against sickle cell disease is ongoing, but with your continued support, we are resolute in our commitment to make a difference.

I extend my deepest appreciation to our donors, member organizations, board of directors, partners, stakeholders, sponsors, supporters, volunteers and the entire SCDAA family. Your contributions, both big and small, have been instrumental in our journey. Together, we are not only celebrating a half century of success but also laying the foundation for the next 50 years of progress, innovation and support.

As we navigate the future, let us remain united in our purpose and determined in our mission to improve the outcomes for those living with sickle cell disease. I invite you to join us in envisioning a future where every individual affected by sickle cell disease can live a life of improved health, dignity and opportunity.

Thank you for being an essential part of our journey.

**In Unity. Toward Progress.**



A handwritten signature in black ink, appearing to read 'Regina Hartfield'.

**Regina Hartfield**

President & CEO, Sickle Cell Disease Association of America, Inc.

## THE BIG PICTURE.

# 2,000

Babies born with sickle cell disease each year.



# 1 in 13

African Americans have sickle cell trait.

# 1 in 100

Hispanic Americans have sickle cell trait.

# 1 in 365

African Americans have sickle cell disease.

# 1 in 16,300

Hispanic Americans have sickle cell disease.

# 43 years

The average life expectancy of someone with sickle cell disease.

## THE MISSION.

To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

## THE HISTORY: YESTERDAY, TODAY, TOMORROW

SCDAA is a globally recognized leader in advancing initiatives for people affected by sickle cell conditions. For over 50 years, we've partnered with diverse organizations, including government agencies and nonprofits, recognizing the importance of collaborative efforts to address the multifaceted needs of those living with sickle cell disease and their families.

**In partnership with SCDAA member organizations and other stakeholder groups, the efforts of our national office focus on six broad areas of emphasis:**



**Research:** SCDAA supports studies to learn more about sickle cell disease, involving our community in medical research to advance our understanding of the disease and improve outcomes for those living with sickle cell conditions.



**Professional and Public Health Education:** SCDAA educates people about sickle cell disease through various channels, empowering caregivers, health care workers and policymakers with knowledge for informed decision-making. SCDAA also organizes events where professionals share the latest insights on sickle cell disease, contributing to the ongoing education of those in the field.



**Advocacy and Legislative Issues:** SCDAA understands the importance of advocacy on a local and national level. We provide training, support and resources to those interested in connecting with their representatives to push for policy changes that positively affect individuals with SCD and their loved ones.



**Patient Services:** Through our network of member organizations, SCDAA collaborates with health care providers to ensure families affected by sickle cell disease receive essential services such as testing, counseling and support.



**Community Services:** SCDAA engages in community initiatives, including summer camps and blood drives, providing fun experiences and supportive essential services to those impacted by sickle cell disease.



**Support to Global Organizations and Practitioners:** SCDAA extends assistance globally, advocating for initiatives to provide genetic counseling, newborn SCD screening, infant and prenatal care, pediatric care and an increased number of adult facilities with expertise in SCD.

# THE IMPACT.

In December of 2023, the Food and Drug Administration made a landmark decision to approve two types of gene therapy to treat sickle cell disease. These therapies are the first of their kind available to members of our community. We are committed to keeping the pulse on these potentially curative treatments as more information becomes available about side effects, costs and more.

## MEDIA OUTREACH



The New York Times

The Atlantic

Bloomberg

ESSENCE

CBS NEWS

NEW YORK

The Washington Post

Over 360 media appearances

as the national voice on gene therapy in print, radio and TV from December 2023 to May 2024 across the United States.



Over 435 million readers, viewers and listeners reached.

“

I've been taking care of kids with sickle cell for over 30 years, and I've been waiting for something like this to happen for a long, long time.

Dr. Lewis Hsu

in The Washington Post, Dec. 9, 2023

**The Washington Post**  
 Date: Saturday, December 09, 2023  
 Location: Washington, DC  
 Circulation (DMA): 288,185 (9)  
 Type of Payment: Newspaper (2)  
 Page: A1.A7  
 Section: Health  
 Keyword: Sickle Cell Disease Association of America

**In milestone, FDA backs treatments for sickle cell**

by CAROLYN Y. JOHNSON

In a major advance, the Food and Drug Administration on Friday approved two gene therapies that target sickle cell disease, one of which is the first commercially available treatment in the United States based on gene-editing technology. The historic move offers hope for a long-overlooked genetic illness that can cause excruciating pain and cut decades off people's lives. It also cracks the door open for a new era in medicine.

One of the new treatments, named Casgevy, is based on CRISPR, a gene-editing tool that moved lightning-fast from a scientific breakthrough in 2012 to a therapy that can alleviate suffering. In the wake of the FDA approval, experts anticipate that treating sickle cell disease will be the first of many medical applications for this technology.

The other treatment, developed by Bluebird bio and called Lyfgenia, uses a harmless virus to insert a gene into a patient's stem cells. The treatments are approved for patients 12 and older who experience repeated pain episodes.

"I've been taking care of kids with sickle cell for over 30 years, and I've been waiting for something like this to happen for a long, long time," said Lewis Hsu, MD, MSc, chief medical officer of the Sickle Cell Disease Association of America and a pediatric hematologist at the University of Illinois.

identified before a federal advisory committee in late October, sharing emotional stories about how the therapy opened up their lives, giving them the ability to work or attend school, be present with their families and imagine a future.

"Prior to therapy, I had focused on the short term. Life was in a state of touch-and-go," Jimi Oughire, 35, who received the treatment three years ago, told the committee. "Long-term planning meant planning for a world without me being able to support my family. Now, these long-term plans include me."

Victoria Gray, 36, a mother and wife, who was the first patient to receive the experimental treatment, said at the meeting that she is finally free from pain crises that felt like being hit by a truck and struck by lightning at the same time, requiring frequent blood transfusions, lengthy hospital stays and three months of opiate treatment.

She predicted that the approval of the gene-editing treatment would have profound effects for many others. "It's going to change the lives positively of many people who are suffering from disease and disorders who now feel hopeless," Gray told the committee. "Once it comes, they can feel hope again, just like I did."

In the United States, an estimated 100,000 people, most with African ancestry, have sickle cell disease. About 20,000 of them have severe symptoms, with frequent pain episodes and the potential for organ damage, and would be good candidates for this therapy, said Peter Marks, director of the FDA's Center for Biologics Evaluation and Research.

**Replacing sickle cells with healthy ones**

sickle-shaped and pliable, to collapse into rigid, sickle-shaped crescents that clump together and die early. The disease varies in severity from person to person, but blockages caused by the clumped cells can trigger crippling pain and starve organs of oxygen.

There are several therapies for sickle cell disease but only one cure: a bone-marrow transplant, typically from a matched sibling. Bone marrow cells from a healthy donor produce normal hemoglobin, allowing transplant patients to live pain-free. But the procedure comes with risks, and only about a fifth of patients are able to find a match.

Fredrikana Copeland-Webster, 39, of Jacksonville, Fla., is one of those patients without a bone marrow match. She has battled two rare diseases: sickle cell and a cancer called neuroblastoma. Her doctors at Nemours Children's Health eliminated her cancer but left her first birthday, but even with a new sickle cell drug that had made her pain less intense, she experiences about four pain episodes per year and, like many sickle cell patients whose pain is exacerbated by cold weather, she goes to sleep with chronic pain all through the winter.

"I began to ask myself why I was able to be cured from cancer and not sickle cell disease," Copeland-Webster, who hopes to be a candidate for one of the new therapies, said in an interview.

Gene editing gets around the problem because it turns a person's own cells into a treatment. Casgevy takes advantage of the fact that before birth, the body produces a form of fetal hemoglobin, and red blood cells that carry it don't sickle. Casgevy disables a genetic switch that represses the production of fetal

## SOCIAL MEDIA BY THE NUMBERS

SCDAA @SCDAAorg - Dec 14, 2023  
 Curious about the latest advancements in gene therapy for sickle cell disease? Get the answers to all your questions in our newest blog post, "Gene Therapy: What You Need to Know." Read more: [buff.ly/3R9HHB](https://buff.ly/3R9HHB)



SCDAA @SCDAAorg - Jan 30  
 Today, the Centers for Medicare and Medicaid Innovation (CMMI) announced the launch of their new Cell and Gene Therapy Access Model, a demonstration aimed at improving access to cell and gene therapy products in the Medicaid program. Read more: [buff.ly/42mZJMc](https://buff.ly/42mZJMc)



SCDAA @SCDAAorg - Jan 26  
 #GeneTherapyQs with SCDAA: Curious about where gene therapy is being offered? Read the full Gene Therapy Warrior FAQ here to learn more: [buff.ly/3R9HHB](https://buff.ly/3R9HHB)

**Q:** Where can I receive gene therapy?  
**A:** Treatment will likely be at an existing bone marrow transplant center that also works with sickle cell disease experts. These may be hard to find. SCDAA will be providing a list of facilities, once identified, on our website.

## Impressions December 2023 to May 2024

f 11,766

in 4,641

ig 10,284

x 3,481

Social Media Impressions Total: 30,172

## DIGITAL COMMUNICATIONS

### Website Engagement

SCDAA Statement on Approval



SCDAA Statement About Gene Therapy Approval



On Dec. 8, 2023, the Food and Drug Administration (FDA) approved two cell-based gene therapies for sickle cell disease (SCD), Casgevy from CRISPR-Vertex and Lyfgenia from bluebird bio. These are the first treatments of their kind available to individuals with SCD in the United States. SCDAA welcomes the approval of these potentially curative therapies which mark major advances in the treatment of sickle cell disease; however, there are valid concerns about accessibility and the potential for adverse effects.

Dr. Lewis Hsu, chief medical officer of the Sickle Cell Disease Association of America Inc. said

Over 2,700 views

**Warrior FAQs**

**Step One**  
 Doctors collect stem cells from your body. The blood-forming stem cells make your red blood cells and other blood cells. The DNA in these stem cells create sickle red blood cells.

**Step Two**  
 The stem cells are taken to a lab. With Casgevy, technicians edit the cells, and Lyfgenia uses a technique called gene addition, so that your stem cells will make red blood cells that don't sickle in your body.

**Step Three**  
 While your stem cells are being edited, you will receive chemotherapy to remove the original cells from your bone marrow.

**Step Four**  
 The newly edited cells are injected back into your body.

Over 4,100 views

### Sickle Cell Connection Newsletter

Gene Therapy Approved

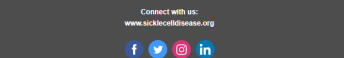


**The FDA has Approved Gene Therapies for Sickle Cell!**

On Dec. 8, 2023, the Food and Drug Administration (FDA) approved two cell-based gene therapies for sickle cell disease (SCD), Casgevy from CRISPR-Vertex and Lyfgenia from bluebird bio. These are the first treatments of their kind available to individuals with SCD in the United States. The approval of these potentially curative therapies marks a major advance in the treatment of sickle cell disease; however, there are valid concerns about accessibility and the potential for adverse effects. Click the buttons below to learn more about these approvals.

SCDAA Statement on Gene Therapy Approval | Gene Therapy: What You Need to Know

Please stay tuned as we learn more about this new therapy. If you would like to support our mission, click here to donate. Thank you for your support!



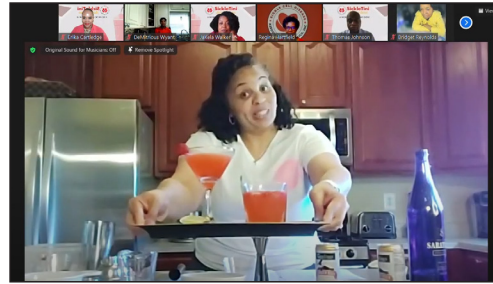
Sent to 10,892



# EVENTS.

## 2024 World Sickle Cell Day and SickleTini Summer Soiree

SCDAA joined the Global Alliance of Sickle Cell Disease Organizations (GASCDO) in recognizing the global theme, "Hope Through Progress: Advancing Care Globally." In recognition of this important day, we hosted a SickleTini Summer Soiree Virtual Happy Hour in June.



### Activities Included:

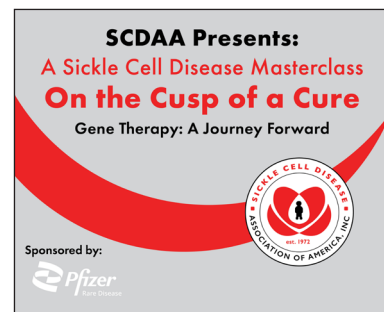
- Cooking Demonstrations
- Educational Videos
- Music

**75+**  
Attendees

## Masterclass Series

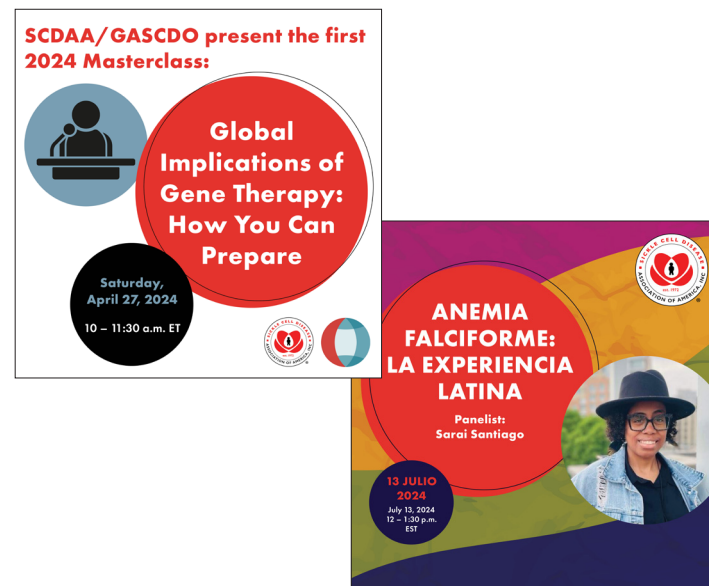
In 2023, SCDAA launched our groundbreaking Masterclass series. These lectures bring together top SCD leaders and community experts to share their expertise on cutting-edge SCD topics.

### 2023 Sessions



- Gene Therapy: A Journey Forward (June)
- All Things Considered – SCD Treatment: A Personal Choice (August)
- The Perfect Red Blood Cell: An SC Dream Redefined (Live at the Annual National Convention - October)

### 2024 Sessions



Over **1,200** Masterclass Registrants | Post-Event Views on YouTube and Website: **Over 1,000**

## Advocacy Days

SCDAA member organizations coalesced on Capitol Hill to meet with representatives and shared why sickle cell matters in May 2024.

**RESULT:** Representative Jonathan Jackson, a Democrat from Illinois' first district, cosponsored the Sickle Cell Care Expansion Act (H.R. 3100).



**13** SCDAA Member Organizations  
**11** Different States Represented  
**23** Office Meetings

## 51st Annual National Convention



**549** attendees  
**40+** scholarships





# INITIATIVES AND PROGRAMS.

## Mental Health & Wellness Initiative

Launched in October 2023, the Mental Health & Wellness Initiative seeks to help sickle cell warriors, caregivers and health care workers understand and take care of their mental health. A comprehensive toolkit was created, and the "I Believe in Therapy" campaign highlights voices from across the community.

## MediAlert Pilot Program

SCDAA and the MediAlert Foundation partnered to help people with sickle cell disease get faster, better emergency care. Now available in all 50 states, the pilot program offers participants a customized smart medical ID card with easy access to their health information and physician-prescribed pain management plan via a QR code.

## Clinical Trial Finder

We continued to advocate for and educate on the importance of clinical trials through the SCD C.A.R.E.S. (Collaboration of Advocates for Research, Education and Science) Consortium.

## Community Health Worker Training 2023



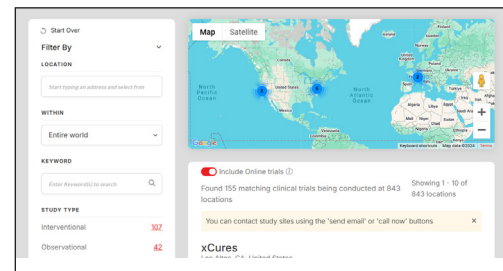
**20** scholarships provided

**SCDAA COMMUNITY HEALTH WORKER TRAINING**  
Beginning **SEPTEMBER 9, 2024**  
9-week virtual course  
Scholarships available!  
Seamless online registration process  
To apply: [bit.ly/SCDAA\\_CHWTraining](https://bit.ly/SCDAA_CHWTraining)  
For more information, contact Kevin Amado, SCDAA community impact & education manager, at [kamado@sicklecelldisease.org](mailto:kamado@sicklecelldisease.org).

**39** people completed SCDAA's National Training Program\*



Toolkit landing page has been viewed **2,200+** times by **1,600+** users



**100+** people used SCDAA's Clinical Trial Finder to search for trials

**P.O.W.E.R ECHO CHW TRAINING**  
Complications of Sickle Cell Disease  
**MARCH 9 12-1 P.M. EST**  
Presented by **Monica Rockwell of SWGA SickleCellAwareness**

**125** people attended a free P.O.W.E.R ECHO CHW Training

\*10 people are currently enrolled in the Fall 2024 CHW Training Program

# THE FUTURE: 50 YEARS FORWARD.

Our journey forward continues, marked by **compassion, innovation and community empowerment.**

## Empowering Lives



Our tightly knit community of sickle cell disease member organizations will continue to provide unparalleled support, guiding individuals living with SCD and caregivers toward a brighter future and a universal cure.

## Igniting Change



## Pioneering Research

Our commitment to encouraging groundbreaking research, which has led to the discovery of promising therapeutic targets, renews hope for even more innovative treatments.



Through ongoing educational workshops, awareness campaigns and advocacy, SCDAA and its member organizations will continue to turn aspirations for change into tangible realities.

As we anticipate the next 50 years of research, solutions and a universal cure, we also look forward to deepening partnerships with advocates and donors who share our mission. Together, we can implement the change that will usher in a new reality for the sickle cell community.

## Our Commitment to Advocacy

SCDAA is dedicated to our mission to advocate for people affected by sickle cell conditions and empower community-based organizations to maximize public consciousness. We are proud to have been recognized for our work with the 2022 Abbey S. Meyers Leadership Award from the National Organization for Rare Disorders. Our fundraising efforts help us continue our outreach and make a difference. On February 29, we recognized Rare Disease Day with our first \$15K in a Day fundraising campaign. It was a huge success! We met our goal and raised \$15,600 to support our cause. Thank you to everyone who participated, donated and joined us for this momentous occasion.

# THE CHAMPIONS.

We express our deepest gratitude to the generous individuals and organizations whose unwavering support has fueled our mission. Their contributions are a testament to the shared commitment to making a meaningful impact on the lives of those affected by sickle cell disease.

## Corporate Sponsors/Contributors



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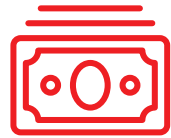
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Crystalle Stripling  
Ryan Strothers  
Crawford Strunk  
Demetria Sullivan  
William Sullivan  
Marcia Taylor  
Shara Taylor  
Veronica Taylor-Williams  
Isaac Terry  
Michael G. Thomas  
James Thomson  
Earnestine Thornton  
Claire Tinsley  
James Tolliver  
Mohamed A. Tounkara  
Kimya Trotter  
Shanida A. Tucker  
Immanuel O. Uketui  
Michael Upshaw  
Marc Vojick  
Yolanda Wade  
Charles Walden  
JaKela Walker  
Christel Walls  
Lauren Walsh  
Joycelyn B. Walters  
Robert & Joycelyn Walters  
Monnette Da Costa Warren  
Carl Warschausky  
Danielle Washington  
Sharon L. Washington

David Watkins  
Charles Watson III  
Regina Wattlely  
R. Watts  
Brenda Wellington  
Bobby J. Wells  
Leah Wiggins  
Sharon Wiley  
Evelyn Wilkins  
Artia Williams  
Candice Williams  
Elizabeth Williams  
Ernest Williams  
Gwendolyn Williams  
Phillip Williams  
J.E.P. Wilson  
Nickeisha Wilson  
Theresa A. Wilson  
Stephen Winter  
Jennifer Woodrum  
Tina Worthington  
Craig Wright  
Sarah Yoman  
Christian York  
Carly Yoshida  
Holly Young  
Zaria Young  
Remi Yuter  
Kateri Zapp

# SUPPORT THE WORK.

SCDAA offers many significant opportunities to support the important work of the organization while providing a tax-deductible contribution to donors.

## One-Time Gifts: Check, Debit Card and Credit Card



The easiest and most popular gifts to SCDAA are unrestricted contributions. SCDAA accepts these contributions via credit or debit card including Visa, Mastercard, Discover and American Express. These contributions can be made online at [bit.ly/SCDAADonate](https://bit.ly/SCDAADonate) or by scanning the QR code to the right.

Checks can be made payable to the Sickle Cell Disease Association of America, Inc., and should be mailed to:

7240 Parkway Drive, Suite 180  
Hanover, Maryland 21076



## Recurring Gifts



If you'd like to support SCDAA's work on a regular basis, monthly gifts can be made via debit card, credit card or checking account. You can set up your recurring gift via our website at [bit.ly/SCDAADonate](https://bit.ly/SCDAADonate) or the QR code above.

## Workplace Gifts: Corporate and Matching Gifts



Workplace giving is a simple and effective way to support SCDAA's mission. Your gift helps us to continue our mission in the search for a universal cure. No matter the size of your contribution, your dollars add up to make a difference in the fight against sickle cell disease.

### Matching Gifts

Consult with your employer and, if applicable, send the completed matching gift form to Erika Cartledge via email at [ecartledge@sicklecelldisease.org](mailto:ecartledge@sicklecelldisease.org) or by calling 410-528-1555.

Matching gifts can significantly increase your support of SCDAA.

### Corporate Giving

Support the Sickle Cell Disease Association of America, Inc., through your company's annual corporate giving campaign. It is a convenient way to make your contribution through regular payroll deductions. SCDAA participates in the Community Health Charities Federation, the largest workplace giving campaign devoted to health. If your employer participates in Community Health Charities campaigns, designate your contribution to Sickle Cell Disease Association of America, Inc.

## Non-Cash Gifts: Stock, Donor-Advised Funds, IRA and Cryptocurrency



Now, you can give the gift of non-cash assets to SCDAA. Whether you make a gift of stock, charitable IRA distribution or cryptocurrency, making a non-cash gift is easier than ever.

### Stock Gifts

To make a stock gift, please contact Reginald Hart at [rphartjr@sicklecelldisease.org](mailto:rphartjr@sicklecelldisease.org) or call 410-528-1555.

### Donor-Advised Funds (DAF), Individual Retirement Account (IRA), Cryptocurrency

Please visit [bit.ly/SCDAA\\_DAF](https://bit.ly/SCDAA_DAF) to make a gift of cryptocurrency or via your DAF and/or IRA.

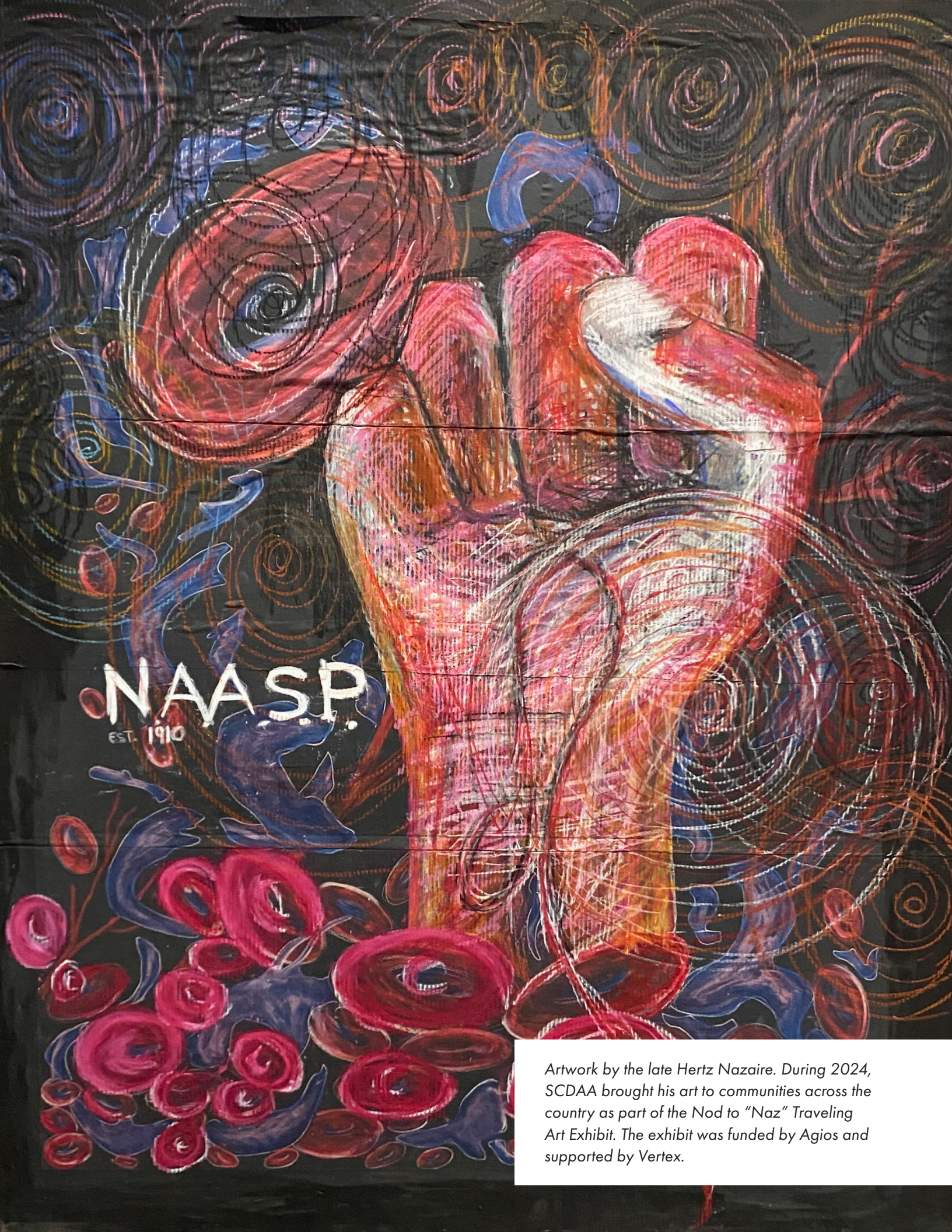
## Planned and Legacy Giving



A planned gift is a contribution that requires planning and offers opportunities for you to support SCDAA now and in the future. Remembering SCDAA in planning for the future gives you the opportunity to leave a legacy in support of our mission. Consider a bequest, charitable annuity or other option.

For more information on how to leave a legacy donation, please contact Reginald Hart at [rphartjr@sicklecelldisease.org](mailto:rphartjr@sicklecelldisease.org) or call 410-528-1555.





Artwork by the late Hertz Nazaire. During 2024, SCDAAs brought his art to communities across the country as part of the Nod to "Naz" Traveling Art Exhibit. The exhibit was funded by Agios and supported by Vertex.





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