

From Our Founder

At the end of every day, I want every warrior to know that we've done everything in our power to ensure that they are strong in body, strong in mind: Alive, well, and living the heck out of their life.

Mission

Voices of Winged Warriors (VoWW) unites the advocacy of caregivers and allies who have lost loved ones to sickle cell disease. VoWW aims to help grievors heal and channel their passion and expertise to radically improve emergency care, mitigate ongoing SCD complications through better healthcare access and maintenance treatment, educate medical associations, and create and impact other changes that transform the landscape of living with sickle cell.

Vision

One day, every person diagnosed with sickle cell disease will be provided with curative treatment at birth, ample insurance to cover care, knowledgeable and non-biased medical practitioners, and equitable public health policies that provide individuals access to a quality of life free of the complications of SCD and its subsequent medical, social, and economic barriers.



"STAT should be the 'stop, drop, and roll,' of care for individuals with sickle cell."
- VoWW Founder & CEO, Stefanie Worth



What We Do

Voices of Winged Warriors fights on behalf of our loved ones lost to sickle cell disease. VoWW raises the voices of caregivers and centers the needs of those who seek healing and individuals living with SCD. We are dedicated to eradicating systemic bias that supports inequitable treatment and care of individuals with sickle cell disease. We collaborate with medical and community leaders to promote best practices in care, advocate for proactive public health practices, and clear pathways to access. We empower the patient community and its allies through credible education and information, and data gathering and dissemination.



Leadership

Voices of Winged Warriors was founded by Stefanie Worth, mother and caregiver of Thomas Ryan White, who passed away in September 2023 at the age of 26 due to complications of sickle cell disease. Her promise – vow – to Thomas is to continue to fight for other individuals with sickle cell in his honor. We fight to keep warriors alive.

The Founding Board will focus on creating VoWW's programming, developing its first strategic plan, and building infrastructure and a financial foundation that ensure future stability. The organization's Board will be augmented by an Advisory Council to provide additional expertise.

Pillars

1) Emergency Care: VoWW is the catalyst behind the Sickle Cell STAT emergency department initiative. STAT supports the work of the American College of Emergency Physicians (ACEP) and the American Society of Hematology (ASH) to help save lives. Through STAT, we also use online surveys to gather patient feedback on emergency treatment and maintenance care.

2) Knowledge, Equity & Accountability: In addition to supporting the work of ACEP and ASH, VoWW aligns its efforts with the standards of the Emergency Nurses Association (ENA), which sets emergency department triage levels. We look forward to collaborating with local chapters of each of these organizations as well as quality improvement groups affiliated with state hospital associations and health departments.

3) Speaking Out: VoWW aims to collaborate with advocacy and patient-focused organizations in each state to support existing and needed public health practices. This includes action around policies that encompass insurance regulations, medical guidelines and those impacting socioeconomic determinants such as healthy food, access to medical care, education, safe and affordable housing, transportation, and other barriers.

4) Education & Economic Empowerment: VoWW aims to work with national sickle cell organizations, local community-based organizations, related health agencies, through social media forums, and other relevant channels to share its emergency department efforts and information learned through its patient surveys to educate and inform patients, caregivers, and allies. VoWW will provide financial literacy, academic support, and educational tools and resources that help warriors obtain and maintain financial independence.

5) Healing & Support: Support for those grieving lost Warriors is woven through each of our action pillars. Our goal is to provide a safe space to gather where we can both mourn and celebrate our loved ones. This may manifest as groups, training, and/or programming focused on healing and ways to move forward.

Advisory Council

Position type:

- Volunteer
- Non-governing

Term of service:

- Advisory Council member: Each Advisory Council member will serve a renewable five-year term.
- Resignation: Council members may resign at any time by email to the Advisory Council President.
- Dismissal: Council members may be dismissed for failure to meet responsibilities.

Time commitment:

Approximately 1-2 hours per month as needed.

Meetings:

- The full Advisory Council will meet 2-3 times per year during 2024 and 2025 and 3-4 times per year thereafter. Ad hoc Council committees will meet as needed.
- Council members are expected to serve on at least one ad hoc Council committee as necessary.
- Council members are welcome to sit on board committees as their ability to fully participate allows.

Financial commitment:

Each Council member is encouraged to donate a personally meaningful gift to VoWW each year.

@sicklecellvow
@sicklecellSTAT

Voices of Winged Warriors - Leadership

Mission

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Qualifications

- A willingness to promote VoWW's mission, vision, and work
- A commitment to upholding VoWW's core values
- Expertise in a particular area of focus for VoWW
- A willingness to support VoWW's fundraising efforts
- Operate with integrity
- Demonstrate curiosity and a willingness to innovate
- Bring a solution-oriented mindset to this work
- The ability to think strategically
- A willingness and ability to represent underserved and marginalized communities.

Responsibilities

- Learn and know the concerns of the communities we serve
- Establish trust within the communities we serve
- Recruit, assemble, and maintain a diverse Advisory Council representative of the communities we serve and VoWW's audiences
- Elect Advisory Council leadership
- Provide leadership, advice, and counsel to VoWW's board, committee members, volunteers (and, eventually, staff) to assist in the fulfillment of VoWW's mission.
- Engage in learning opportunities to better understand the communities VoWW serves
- Respect the experiences of all who bring their voices and lived experiences into the boardroom and the organization
- Ensure legal and ethical integrity
- Follow VoWW's bylaws, policies, and board resolutions
- Sign an annual conflict-of-interest disclosure and update it during the year if necessary, as well as disclose potential conflicts before meetings and actual conflicts during meetings
- Maintain confidentiality about all internal matters of VoWW
- One VoWW Board Director will serve on the Advisory Council

To apply: Visit www.sicklecellvow.org/leadership

P.O. Box 760142, Lathrup Village, MI 48076-0142 | www.sicklecellvow.org

Board of Directors

Position type:

- Volunteer
- Governing with fiscal/fiduciary duties

Term of service:

- Member: Each board member will serve a three-year term, renewable once.
- Officer: Each officer will serve a two-year term, renewable once.
- Resignation: Board members may resign at any time by email to the Board Chair.
- Dismissal: Board members may be dismissed for failure to meet responsibilities.

Time commitment:

- Members: Approximately 1-2 hours per month during 2024 and 2025. Thereafter, approximately 2-4 hours per month.
- Board officers and committee leads: Approximately 2-3 hours per month during 2024 and 2025. Thereafter, approximately 3-4 hours per month.

Meetings:

The full board will meet quarterly. Standing board committees will meet between board meetings. Ad hoc committees will meet as needed. Founding board members will determine meeting dates and times. Board members will be expected to attend 75 percent of full board meetings. Board members are expected to serve on at least one board committee.

Financial commitment:

Each board member is expected to support VoWW as one of their top three charitable causes. Each board member is required to donate a personally meaningful gift to VoWW each year.

To apply, visit:

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Voices of Winged Warriors - Leadership

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Qualifications

- Believe in VoWW's mission, vision, and core values.
- A willingness to promote VoWW's mission, vision, and work
- A commitment to upholding VoWW's core values
- A willingness to support fundraising efforts necessary to execute VoWW's programs, events, and activities
- Knowledgeable within an area of expertise necessary to govern an effective, impactful, compassionate organization
- Be a member of one or more of the communities we serve
- Operate with Integrity
- Demonstrate curiosity and a willingness to innovate
- Bring a solution-oriented mindset to this work
- The ability to think strategically in order to implement approaches to address concerns of VoWW's communities within societal challenges and inequities
- A willingness and ability to represent underserved and marginalized communities

Responsibilities particular to the founding board

- Develop VoWW's core values and guiding principles.
- Establish trust within the communities we serve
- Recruit, assemble, and maintain a diverse board representative of the communities we serve and bearing the skills necessary to govern an effective, impactful, compassionate organization
- Develop and adopt VoWW's By-laws
- Elect board officers
- Create the organization's initial strategic plan

Responsibilities of each board member

- Know the organization's mission, policies, programs, and needs, and understand its purpose
- Faithfully read and understand the organization's financial statements and board materials in advance of meetings
- Serve as an active advocate and ambassador for the VoWW
- Fully engage in identifying and securing the financial resources and partnerships necessary for VoWW to advance its mission and thrive
- Provide access to a network of community and corporate leaders who can facilitate VoWW's ability to achieve its mission and strategic goals, including fundraising, promotion, programming, and public policy
- Provide leadership, advice, and counsel to VoWW's board, Advisory Board, committee members, volunteers (and, eventually, staff) to assist in the fulfillment of VoWW's mission.
- Engage in learning opportunities to better understand the communities VoWW serves
- Respect the experiences of all who bring their voices and lived experiences into the boardroom and the organization
- Uphold the legal duties and laws regarding nonprofit governance
- Follow VoWW's bylaws, policies, and board resolutions
- Sign an annual conflict-of-interest disclosure and update it during the year if necessary, as well as disclose potential conflicts before meetings and actual conflicts during meetings
- Maintain confidentiality about all internal matters of VoWW

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INSTRUCTIONS: To be considered for membership on VoVW's Board of Directors or Advisory Council, please complete this form and return with your resume/CV and photo to sicklecellvow@gmail.com. Please include a brief explanation of why you'd like to join VoVW's leadership in the body of your email. Note: If you are selected and join VoVW's Board or Council, portions of your information may be used to promote the organization. If you have any questions, please feel free to call Stefanie at (833) 688-I-VOW (4869).

I'd prefer to be considered for a role on the: VoVW Board of Directors VoVW Advisory Council Either
Would you also like to serve as an Officer? No Maybe If yes: Chair Medical Dir. Secretary Treasurer

Name: (As you'd like it to appear publicly written) _____

Nickname: _____ **Your Pronouns:** She/Her He/Him They/Them

Company/Work Affiliation (or retired): _____

Company/Work Title (or retired): _____

Occupation/Primary Skill Set: _____

City / State / Country: _____

(NOT FOR PUBLIC USE) Preferred Phone: _____

(NOT FOR PUBLIC USE) Preferred Email: _____

What is your connection to the mission of VoVW? (Check all that apply)

- Living with sickle cell disease
 Caregiver to someone with sickle cell disease (living deceased)
 Medical professional I care/treat individuals with SCD Area of Practice/Expertise _____
 Health-adjacent professional (social worker, educator, pharmacist, insurer, etc.) I provide care for people with SCD
 Scientist, researcher, representative of a pharmaceutical company that develops treatments for SCD
 Media representative who has the power and ability to promote our cause positively
 Ally to individuals with SCD (personal professional) Please specify: _____
 None / The public at large

Please check any of the following skills or experience that you will bring to the board:

- | | |
|--|--|
| <input type="checkbox"/> Finance, accounting | <input type="checkbox"/> Public relations, communications |
| <input type="checkbox"/> Nonprofit experience | <input type="checkbox"/> Advocacy, public policy |
| <input type="checkbox"/> Counseling, therapy | <input type="checkbox"/> Legal |
| <input type="checkbox"/> Contacts, networking | <input type="checkbox"/> Management, administration <input type="checkbox"/> |
| <input type="checkbox"/> Fundraising, special events | <input type="checkbox"/> Member of <input type="checkbox"/> ASH <input type="checkbox"/> ACEP <input type="checkbox"/> ENA Other _____ |
| <input type="checkbox"/> Human resources | <input type="checkbox"/> Other _____ |

DEMOGRAPHIC INFORMATION: For internal use only to help track board/council composition and diversity.

Age _____ **Your birth day and month** (Optional, for celebration only) _____

Race & Ethnicity (How do you publicly identify?):

- Asian American/Pacific Islanders/Asian Black/African American/African Hispanic/Latino/Latina/Latinx
 Middle Eastern White/Caucasian/European Multi-Racial/Multi-Ethnic (2+ races/ethnicities) I'd rather not say

Gender Identity (How do you publicly self-identify?):

- Female Male Non-binary Transgender Not transgender (cisgender - a person's who gender is the same as the sex assigned to them at birth) Rather not say

Sexual Orientation (How do you publicly self-identify?): LGBTQIA+ Heterosexual or Straight Rather not say Other

Disability Status (How do you publicly self-identify?):

- Person with a disability Person without a disability I'd rather not say Unknown