

**INTERNATIONAL
VASA PREVIA
FOUNDATION**



**SOPHIE'S WALK
CAPTAINS' MANUAL**



International
Vasa Previa
Foundation

The International Vasa Previa Foundation, Inc. (IVPF) is a non-profit, tax-exempt corporation organized and operated exclusively for charitable and educational purposes in accord with Sec. 501(c)(3) of the Internal Revenue Code of 1986.

More specifically, the corporation is organized to provide prevention and detection information and bereavement support to the general public and health care professionals regarding the potentially fatal prenatal condition known as vasa previa.

Corporate Address:

2109 5th Street
Moline, IL 61265 USA
267-790-6693
info@vasaprevia.com

Tax Number:

36-4450161

Mailing Address:

PO Box 272293
Boca Raton, FL 33427 USA

Website:

<http://IVPF.org>

Get involved in creating awareness of vasa previa!

Request participating level membership in the IVPF

by sending an email to: info@vasaprevia.com

Or visit <http://IVPF.org/contact/member.htm>

Preface

The purpose of this document is to enable and empower you to raise funds and spread awareness of vasa previa to the world through Sophie's Walk for Vasa Previa, an IVPF sponsored event, while at the same time provide some structure and guidelines for your activities in this area within and on behalf of the IVPF. The procedures contained herein are based on IVPF policies, operating procedures, and experience previous Walk Coordinators have had producing this event. They have been developed for your use with the good of the Foundation in mind.

It is important that each Walk Captain perform in accordance with these procedures, utilizing approved materials, statements, and messages developed for the express purpose of providing a strong unified IVPF effort worldwide. Captains not operating in such fashion run the risk of misrepresenting the IVPF and its goals, and could conceivably damage the efforts of the organization at large. There are many opportunities to serve the IVPF. Sophie's Walk is one of the most rewarding and we thank you wholeheartedly for participating in and organizing this important event!

Our success depends on the generosity of members like you and the time you are able to devote to bringing awareness of vasa previa to the world. Joining together to help educate others may save future babies from such an untimely death. Your contribution to this cause is very much appreciated! Please feel free to contact the Walk Coordinators any time you have questions or suggestions.

Most sincerely,

The IVPF Staff and Directors



Sophie's Walk for Vasa Previa

Overview

Thank you for volunteering to organize Sophie's Walk for Vasa Previa! The International Vasa Previa Foundation (IVPF) exists to raise awareness of vasa previa and its risk factors with an eye towards routine prenatal diagnosis and management of the condition so that infants can be saved from its horrible demise. We are sorry you have reason to know us. But we welcome your participation and help in this important cause!

Sophie's Walk is held in memory of Sophie Isabelle Macadar who died because of undiagnosed vasa previa. It is held each year on the first weekend of October. On this day people the world over walk to support IVPF efforts to end infant death from vasa previa.

Each individual walk is usually organized by a relative or good friend of someone who had vasa previa, most commonly the parents. While Sophie's Walk is always called Sophie's Walk everywhere, local vasa previa babies are the reason for the walk. Captains are encouraged to write and hand out the local baby's story during the Walk. IVPF will format each baby's story on Walk letterhead for this purpose. IVPF provides all materials and will be there every step of the way.

Online Walk meetings will be held, typically once per month, more often when it gets closer to the walk. Captains are expected to attend these meetings to report on their activities and obtain guidance and materials in a timely fashion.

Very large Walks or Walks in locations that require permits and insurance require some additional organization. Please contact the Walk Coordinators as soon as possible if your chosen walk location requires permits and/or insurance.

The International Vasa Previa Foundation believes that infant death due to vasa previa is an avoidable tragedy. Thank you once again for your participation in this important fundraising event!

Captain's Roles and Responsibilities

- Attend the meetings! It is difficult to provide information individually to each and every Captain.
- Ascertain and reserve a location for your Walk early. Contact the Walk Coordinators if your location will require event permits and insurance.
- Get as many walkers as possible. Register them yourself at <http://SophiesWalk.org/walk> if they do not have internet access.
- Procuring local sponsors for prizes, food, and donations makes your event more successful and fun.
- It is suggested that Walk Captains ask some of their walkers for volunteers to alleviate some of the work, especially if additional activities are planned.
- Captains are responsible for contacting registered walkers promptly with specific information regarding walk time and location.
- You will receive all Walk materials (such as brochures, posters, and waivers) from the Walk Coordinators.
- Send the local Walk's baby story to SophiesWalk@vasaprevia.com so that we can format it on Walk letterhead for you to hand out at the Walk.
- IVPF materials, training, and a media list will be provided to Captains desiring to contact their local media.
- You will be responsible for issuing receipts for donations under \$20 that are collected the day of the walk. All donations are tax-deductible.
- Take plenty of pictures! Submit them as soon as possible to SophiesWalk@vasaprevia.com so that we can get them up on the website.
- You will need to submit a post event report. This post event report is very important for the planning of future events. This document will be provided to you shortly before the walk.
- Promptly send donations collected on the day of the Walk to the IVPF at PO Box 272293, Boca Raton, FL 33427 USA
- Information needed for fundraising purposes: The International Vasa Previa Foundation is a 501(c)(3) non-profit tax-exempt charitable organization. Corporate address = 2109 5th Street, Moline, IL 61265 USA. Tax ID = 36-4450161.

Attend Meetings

Pick a location early

Get Sponsors

Promote your event

Take plenty of pictures

Complete Event Report
and Send in \$\$\$



It's the Day of the Walk! What do I do now?

- Get up early to put out your signs if you haven't done that the day before.
- Put out food, if you have any, and water.
- Register people who've not pre-registered.
- Make sure EVERY volunteer and participant signs a waiver. No exceptions!
- Hand out your baby's story and IVPF information.
- Collect and secure donations.
- WALK! And take lots of pictures!!!
- Hand out or auction off donated items, if you have any.
- Relax and have fun with your walkers!
- Thank your walkers and volunteers for being heroes. Their participation saved precious infant lives.
- Clean up the Walk site.

After the Walk

- Email your pictures to SophiesWalk@vasaprevia.com so we can put them on the website.
- Promptly send donations, sponsor contribution forms and waivers to the IVPF at PO Box 272293, Boca Raton, FL 33427 USA
- Send in a post event report (by email is fine).
- Special recognition is important! Let the Walk Coordinators know of any exceptional volunteers and participants that you would like to nominate for the International Vasa Previa Foundation's Humanitarian Service Award.
- Relax and know that you have our appreciation for a job well done!!! You are a hero in our eyes!

COLLECTING DONATIONS AND PRIZES

*Asking businesses for donations and prizes
is easy once you get the hang of it!*

Make your stops while out running errands. It is easiest to solicit local businesses where the owner is present and running the day to day operations.

Tell potential sponsors that vasa previa is one tragedy that we CAN do something about. And that we MUST do something about it because these babies die otherwise. Most are very willing to help out.

Go with a list in mind of what you need. If they say no to one request, just keep going down your list of needed items. What you are asking for is 1- donations in the form of gift certificates or coupons to hand out or raffle off; 2- bottled water; 3- putting up a poster in their window (bring your own tape to hang it up); and 4-donations of money (from larger corporate sponsors).

Tailor your requests to the nature of the shop or restaurant. Don't forget places like flower shops, hair dressers, even auto repair shops. These places can make use of the free publicity and your walkers will appreciate the coupons and gift certificates. Also ask for gift certificates from your local sales consultants of Discovery Toys, Usborne Books, Pampered Chef, etc.

Your approach is important. Assume that they will be able to help you in some way. Be polite, even if they can't or won't help in any way (there's always next year!)

Corporate businesses usually require that that you contact their main office for donations. Typically this requires at least 6 weeks lead time for them to process your request. Many can be contacted by fax or phone but will require a sponsor letter on company letterhead. Always follow up. Please remember that you are representing the IVPF if you meet with them in person.

What do you say when they ask you about vasa previa? Here's what you say: Vasa previa is a complication of pregnancy. Without prenatal diagnosis and an early C-section the baby is almost certain to die. With diagnosis and C-section, nearly 100% of them survive. Research shows it can be diagnosed and survived. Sophie's Walk exists to eliminate infant death from vasa previa.

**it only takes a moment
to diagnose life...**

