European Reference Network
VASCERN

Pregnancy, Family Planning & Vascular Anomalies

What you need to know about family planning, pregnancy, delivery & contraception when living with a vascular anomaly

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Introduction

This booklet is for women (and men) who are planning to have a baby, or who are already pregnant and have been diagnosed with a Vascular anomaly (VA). Its goal is to offer guidance and information on how to manage pregnancy and childbirth in these situations. While it offers general recommendations, it is not intended to cover every possible scenario.

Vascular anomalies include a range of conditions involving abnormal blood and/or lymph vessels. The diagnosis may have been made long ago based on physical exams and/or imaging tests; however, as our understanding of these conditions improves and new diagnostic techniques become available, experts may be able to identify VA more accurately. Obtaining the correct diagnosis is especially important for women who wish to become pregnant.

It is important to consult an expert/referral centre (specialised in VA, available on the VASCERN website) to receive appropriate advice and care, as different types of VA require different approaches.

Looking for resources and support ?

- Want to understand more about your condition? Visit the VASCA web page on the VASCERN website.
- Looking for VA specialists near you? Check our map of healthcare providers to find expert centres across Europe.
- Is your doctor unsure what to do next? If you live in Europe, your doctor or gynaecologist can submit your case (with your consent) to the Clinical Patient Management System (CPMS) so it can be reviewed by a panel of experts.
- Need community or patient support? Find trusted patient organisations via the VASCA patient organisations page.

Planning for pregnancy

Key points to remember

Individual assessment
Every woman with a VA should receive a full assessment so that she can decide if she wants to have a child.

Consult with an expert
If you are considering pregnancy, discuss your plans with a physician who specializes in vascular anomalies and works at an expert/referral centre. This discussion is crucial in preparing for a safe pregnancy and delivery.

Local support
In cases where there is no specialised expert/referral centre nearby, your local gynaecologist (at your nearest hospital) can contact specialists through VASCA-VASCERN and its Clinical Patient Management System (CPMS), if in Europe, to ask for assistance.

Monitoring during pregnancy
You may need close monitoring during your pregnancy, which will be coordinated between your expert/referral centre and your local gynaecologist.

Delivery Planning
Decisions about where to give birth will depend on your specific VA, including its location and severity. This could mean giving birth at your local centre/obstetrician or at a specialised expert/referral centre.

Each pregnancy is unique
As circumstances may change, the analysis/ thought process for another pregnancy should be done each time a pregnancy is considered. The VA could have changed (evolved) since a previous pregnancy, or the mother/father could have received medical treatment in between.

Understanding these points can help you navigate the decision-making process about a pregnancy while managing a VA. These answers will depend on the VA you are living with, its location, extent and progression.

How your vascular anomaly might affect your pregnancy

If you have **VA in the pelvic area**, it is important to have a consultation with a gynaecologist before getting pregnant. This will help to clarify the extent of the condition and what to expect during pregnancy and delivery due to the growth of the uterus, hormonal changes, and increased blood flow observed in these conditions.

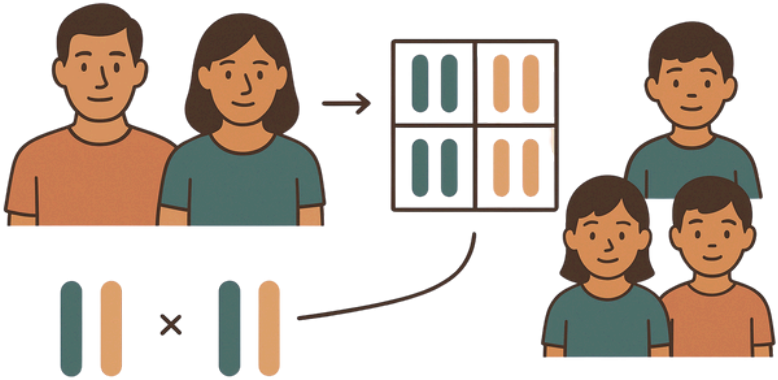
Pregnancy can sometimes worsen certain VAs, due to hormonal changes or other reasons. For example:

- In arteriovenous malformations (AVMs), disease-progression has been reported, in some cases with and in some cases without regression after delivery. It is important to discuss this with your expert/ referral centre before getting pregnant. AVMs from HHT might have a different behavior; this it is not covered in this document.
- In venous malformations (VM), disease-progression can be seen due to increased pressure in veins; it is not always clear whether this progression reverses after delivery.
- In slow-flow vascular malformations (such as venous malformations, veno-lymphatic malformations or Proteus syndrome, PIK3CA-related overgrowth spectrum (PROS) such as Klippel-Trenaunay syndrome , CLOVES) there may be a higher risk of blood clotting (thrombosis). There is also a higher risk for bleeding / tendency to haematoma. These risks are especially elevated if the slow-flow vascular malformation patient has localized intravascular coagulation (LIC) during pregnancy.

Inheritance

Most VA are not inherited and will not be passed on to your children. However, some types can run in families. These include:

- Glomuvenous Malformation
- Capillary malformation-arteriovenous malformation (CM-AVM)
- PTEN Hamartoma Tumor Syndrome (Cowden syndrome)



If you are unsure about your genetic risk, it is a good idea to consult a geneticist at your expert/referral centre for vascular anomalies.

Targeted Therapy

If you are being treated with a targeted therapy such as sirolimus, alpelisib, trametinib, thalidomide or other medicines, it is important to stop taking them at least 3 to 6 months before trying to get pregnant.

Be sure to discuss your pregnancy plans in advance with your local gynecologist and/or expert or referral centre.

Recommended contraceptives when you have a VA

If you have a slow-flow vascular malformation (such as venous malformations, veno-lymphatic malformations, or Proteus syndrome PIK3CA-related overgrowth spectrum (PROS) such as Klippel-Trenaunay syndrome, CLOVES syndrome), there may be a higher risk of thrombosis.

This risk can increase with certain medications, such as birth control pills that contain estrogens.

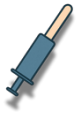
Avoid contraceptives with high doses of estrogen.

Instead, other types of contraceptives can be suggested, such as:

Progesterone contraceptives such as desogestrol

A small hormone-releasing device inserted into the uterus (Mirena IUD)

A small hormone-releasing implant under the skin (Implanon)



On the other hand, if you have a fast-flow vascular malformation, there is usually no increased risk of blood clotting. In this situation, there are no specific birth control guidelines that your doctor would need to follow.

Medication use before and during pregnancy

General

If you are considering getting pregnant, it is important to review the medications you are taking and weigh the benefits against any potential risks to you and your child. It is best to do this before you get pregnant, but it is still important to review as soon as possible if you are already pregnant.

Always discuss the use of any medicines with your doctor and your local obstetrician or gynaecologist. If necessary, consult a specialist at your referral centre.

Never make decisions about stopping or starting medication on your own.

Blood thinners

Some patients with slow-flow vascular malformations may be prescribed blood thinners such as direct oral anticoagulants (DOACs) such as rivaroxaban, apixaban.

It is recommended to switch to a different anticoagulant, such as low-molecular weight heparin (LMWH (Clexane, Fraxiparine)), before and during pregnancy.

If a patient with slow-flow malformations has LIC (localised intravascular coagulation), they must be treated with LMWH before, during and after pregnancy to avoid complications during pregnancy, delivery and early postpartum.

Targeted therapy (medication aimed at systemic inhibition of the VA)

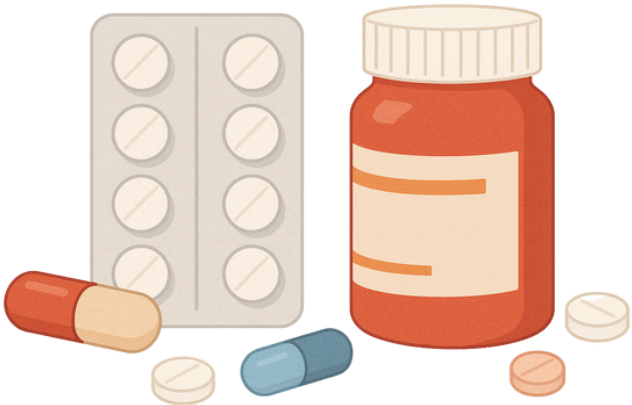
People with VA may use targeted medications such as sirolimus, alpelisib, trametinib, thalidomide (or other targeted therapy). It is advised to use effective contraception for both women and men who are taking these medications.

It is advised to stop taking these medications at least 3 to 6 months before trying to conceive.

It is advisable to discuss stopping of these therapies with your prescribing physician at your expert/referral centre before conceiving.

Some years ago there were concerns that both sirolimus and alpelisib could lead to infertility. Current evidence suggests that the effects of sirolimus on gonadal function and fertility are generally minimal and reversible (for more information, see the VASCERN-VASCA Consensus Statement on Sirolimus and Fertility).

There is no data currently available on alpelisib. More research is expected in the future. However, this uncertainty should be taken into account when advising people of childbearing age about starting targeted medications.



Precautions to take before, during, and after pregnancy

Pre-conception

- *Adopt a healthy lifestyle*: Focus on a balanced diet and regular exercise.
- *Smoking and alcohol consumption*: It is advised to stop (or reduce as much as possible) smoking and alcohol consumption for a healthier pregnancy
- *Review medications*: Some medications should not be taken during pregnancy. Discuss your current medications with your doctor or local gynaecologist and, if necessary, consult a specialist at your expert/referral centre.
- *Consult a specialist:* If your VA is likely to involve or does involve the pelvic area, a pre-conception consultation should be performed at an expert/referral center for VA in conjunction with your gynecologist.

An MRI of the pelvic area and spine (especially if you are considering an epidural anaesthesis) needs to be done.

During pregnancy

Depending on your type of VA, its location, and your symptoms, you may need to:

- Wear compression stockings, especially if the VA is localised in the legs (or arms). These can help manage discomfort and pain.
- *Take low-molecular weight heparin*: This medication may be prescribed if you have a painful venous malformation, or a slow-flow vascular malformation with large varicose veins, to prevent blood clots.
- In general, any treatment that requires X-rays (sclerotherapy, arteriography) should be avoided during pregnancy to avoid radia-

tion to the foetus. However, it would be up to the team of specialists to determine if any medical gesture is needed during this period to control any evolution of the VA. On the other hand, MRI can be performed during pregnancy.

- Arrange medical check-ups during pregnancy to monitor disease activity/progression (coagulation).

Delivery

- Work with your gynaecologist and the vascular anomaly expert/referral centre to prepare a personalised delivery plan. Make sure you plan this well in advance.
- In the event of an early/emergency delivery, make sure the local team contacts your gynaecologist or the specialist at the expert vascular centre.

Keep all contact information handy for this purpose.

Postpartum

- If your VA causes coagulopathy, you may need to take low-molecular weight heparin during pregnancy and continue after delivery. The exact medication and proper dose must be prescribed by a referring haematologist.

What to Remember

- Always consult an expert in vascular anomalies before pregnancy or stopping/starting a medication.
- Stop targeted medications (e.g., sirolimus, alpelisib) 3–6 months before conception, but consult your VA-specialist first.
- Some VA types may worsen during pregnancy due to hormonal and circulatory changes.
- Every pregnancy is unique — always reassess even if you have been pregnant before.
- Plan your delivery with both your local and referral specialists.

For men living with a vascular anomaly

- It is important to stop targeted medication 3 to 6 months before conception. It is important to use contraception consistently.
- Use of thalidomide is under strict legal requirements regarding contraception.
- There is currently no evidence that sirolimus affects the fertility of men. No data is currently available on alpelisib; see the section above on ''*Medication use before and during pregnancy*.''

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European Reference Network

VASCERN

Gathering the best expertise in Europe to provide accessible cross-border healthcare to patients with rare vascular diseases

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million affected). These include arterial diseases (affecting the aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently comprises 48 expert teams from 39 highly specialised multidisciplinary HCPs coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realize the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information is available at: www.vascern.eu

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