




**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)



# Pregnancy and Primary Lymphedema

Validated by the Pediatric and  
Primary Lymphedema (PPL)  
Working Group

Nele Devoogdt, Guido Giacalone, Pernille Henriksen,  
Tonny Karlsmark, Vaughan Keeley\*, Manuela  
Lourenço Marques, Sahar Mansour\*, Christoffer  
Nissen, Susan Norregaard, Michael Oberlin, Tanja  
Planinšek Ručigaj, Sinikka Suominen, Stéphane  
Vignes, Kirsten Van Duinen, Sarah Thomis,  
Robert Damstra.

\*HCP member before Brexit, January 1st, 2021

# Pregnancy and Primary Lymphedema

## Family planning with lymphedema

**Question: What is recommended with regards to contraception pills since they are said to make you retain water? Will they make the lymphedema worse?**

Answer: Typically, the side effect of retaining water depends on the estrogen in the contraception pills. Mini pills without estrogen or micro pills, a low-dose combination of estrogen and progestin, cause no retention of fluid.

**Question: I have primary lymphedema/my partner has primary lymphedema. Should we get genetic testing before a pregnancy?**

Answer: Some primary lymphedemas are inherited. Depending on the type of primary lymphedema it could be reasonable to get in touch with a genetic counselor.

Some primary lymphedema can be caused by an inherited genetic fault. Many of the genes can be inherited as a 'dominant' condition. If one of you has a dominant genetic condition causing your primary lymphedema, there is a 50% chance that your baby will inherit this condition. Genetic testing may give you more information about the risk of this happening but the chance of identifying a genetic fault is currently only approximately 10%. This is probably because not all the genes that can cause primary lymphedema have been discovered. The baby may inherit the genetic susceptibility to lymphedema but may not develop swelling for a number of years.

If you or your partner had swelling of the feet at birth, the baby may also present with swelling of the feet at birth. This can sometimes also be seen in the antenatal scans in the third trimester. It does not cause any pain or discomfort to the baby and can be managed with compression after birth. Very occasionally, the antenatal scan can show some fluid in the baby's lungs but this usually resolves itself but will need monitoring by the obstetrician.

**Question: What is the procedure for genetic testing and which primary lymphedema should be tested for while planning for a family?**

Answer: It is probably best for you to see a genetics doctor or genetic counselor who can arrange genetic testing for you and explain the test to you. They will also be in the best position to explain the results to you and the implications for your baby. The genetic test is usually a simple blood test but it may take some time to get the result. However, this test is not available in all countries. If no genetic fault is identified, it does not mean there is not a genetic cause of your lymphedema.

**Question: Are there any implications for my pregnancy or the baby that I have lymphedema?**

Answer: No, lymphedema does not affect the development of the baby. However, some forms of primary lymphedema can be inherited by the baby.

**Question: What if my doctor cannot advise me about pregnancy with lymphedema? Whom should I ask for advice?**

Answer: Look for information on the VASCERN website to find an expert center in your country.

---

*The above information provided is not intended to replace professional health care advice.  
Patients must consult with a qualified physician for diagnosis and treatment.*

## Pregnancy with lymphedema

### **Question: Will my lymphedema get worse when I get pregnant?**

Answer: There are very few clinical studies to answer this question. However, the few studies that have been done have shown that pregnancy did not carry a major risk of exacerbating leg lymphedema.

### **Question: Can my lymphedema spread to other body parts when I am pregnant?**

Answer: No data about this question is available. Leg edema is very common during late pregnancy so it could arise a swelling even on the other leg caused by other factors like increased fluid volume. To exclude pre-eclampsia, get your blood pressure and your protein excretion in urine checked.

Swelling of the legs is common during late pregnancy so it is possible that a woman with unilateral lymphedema will develop swelling in the unaffected leg.

Any woman with marked swelling of the legs should be checked for preeclampsia, by checking blood pressure and protein excretion in the urine.

### **Question: How will I know if any additional swelling is normal or if my lymphedema is getting worse?**

Answer: Edema (swelling) in the legs in late pregnancy is very common, but it is symmetric which means both legs would normally be affected.

### **Question: I wear pantyhose compression. Is it dangerous to wear compression on the stomach when I am pregnant?**

Answer: During early pregnancy, you can continue to wear pantyhose. In the second part of pregnancy, you can switch to a pantyhose compression without pressure in the stomach part.

### **Question: How can I manage to don and doff my compression stocking(s) with a big stomach?**

Answer: If possible, ask your partner to help you and use accessories from the medical store. There are many kinds of donning and doffing devices available.

### **Question: Can I use the pneumatic compression pump on my leg(s) while I am pregnant?**

Answer: Yes. A pneumatic compression pump for the leg(s) can help with pregnancy-induced swelling in late pregnancy.

### **Question: Are there additional risks of getting cellulitis /erysipelas due to pregnancy?**

Answer: Ensure good skin care throughout your pregnancy and watch out for any skin changes. Continue to manage your lymphedema with compression. Hormonal changes during pregnancy can affect the skin so take good care of the skin and watch out for any skin changes. Check the "Cellulitis Flowchart" for signs and symptoms of cellulitis.

**Question: If I get cellulitis while pregnant, can I still take antibiotics? Are some antibiotics better to take while pregnant?**

**Answer:** If you get cellulitis/erysipelas during pregnancy, it is important to start antibiotics immediately. Your doctor can advise you on the kind of antibiotics that are safe during pregnancy or while you breastfeed and do not have side effects on your baby.

---

*The above information provided is not intended to replace professional health care advice.  
Patients must consult with a qualified physician for diagnosis and treatment.*

## Delivery and Postpartum care with lymphedema

**Question: Is there a delivery method more suitable for those with lower limb lymphedema?**

Answer: The delivery method, vaginal or via cesarean, should be discussed with your obstetrician to evaluate your unique situation for the safety of you and your unborn child(ren). As such, there are no contraindications for either when you have lower limb lymphedema. However, if you have severe genital lymphedema, with lymph cysts and recurrent erysipelas, both pros and cons should be discussed. A consultation should be made with the clinician who follows you for your lymphedema and the obstetrician.

**Question: Can you have an epidural when you have lower limb lymphedema?**

Answer: There are no contraindications for having an epidural if you have lower limb lymphedema. As in any other intervention, an aseptic technique will be used, to reduce the risk of infections. It should not influence your lymphedema, but make sure the anesthesiologist has been informed of your condition.

**Question: Do I need to wear compression garments in the hospital when I give birth?**

Answer: If you have thigh-high or knee-high compression garments, you can wear them.

**Question: Can I use the pneumatic pump on my arm while I am breastfeeding?**

Answer: Yes. There is no contraindication.

**Question: I have lymphedema of the arm, will carrying my baby make my lymphedema worse?**

Answer: Muscle activity is important for patients with lymphedema. Try to interchange the side where you carry your baby and use a baby carrier to avoid unnecessary strain.

---

*The above information provided is not intended to replace professional health care advice.  
Patients must consult with a qualified physician for diagnosis and treatment.*



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 concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, 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 realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information available at: <https://vascern.eu>

Follow us on



Co-funded by  
the Health Programme  
of the European Union