

Questions to ask Physicians/Providers at Vascular Anomalies Centers

Here is a guide to help answer questions that you might have when you discuss the CLOVES diagnosis with HealthCare providers

1. How many CLOVES patients have you diagnosed/evaluated/seen?
2. If my child sees multiple specialists at your Vascular Anomalies Center, how often/when do those specialists consult about my child's needs?
3. Can you tell me what specific manifestations of CLOVES my child has?
4. Based on my child's specific lesions/vascular malformations/overgrowth etc, how often would you recommend imaging? What kind?
5. What about Wilms' Tumor? There is a greater risk of Children with overgrowth disorders to develop this. What is your recommendation for screening?
6. How often should my child be evaluated by your Vascular Anomalies Center?
7. What other hospitals would you recommend for consultation and follow-up?

At what point would you recommend:

1. Resection of internal/external lipomas
2. Resection of overgrown extremities/trunk/digits
3. Resection/interventional radiology of vascular malformations
4. Do you have a social worker available to my family/my child to discuss issues of disability, physical difference/disfigurement, and other emotional issues that may arise related to this condition?
5. Knowing my child's specific manifestations of CLOVES, can you tell me if there is any way I can be proactive and/or anything we should be watching for?
6. Do you recommend any other treatment options besides "wait and see", surgery or interventional radiology? Are there any anti-angiogenesis medications/non-surgical options for children with CLOVES currently?
7. If I have questions after I leave here, or concerns down the road, who shall I contact? Is that person accessible to me via email?