



### Establishing a Patient Care Coordination Note in EPIC

In order to have better outcomes in the emergency department for people with genetic aortic and vascular conditions, a **Patient Care Coordination Note (PCCN)**, can provide triage nurses and ER physicians, with life-saving information for these rare conditions. **This patient care coordination note** appears in the upper left hand corner in red, when you open the outpatient chart under snapshot and in some other views depending on how your EPIC is set. The PCCN can outline critical information to treat patients with rare conditions. See image below for example.

The Marfan Foundation recommends that each institution, place critical care instructions in patient care coordination notes in hopes that during emergency situations patients are triaged quickly and the proper testing is undertaken.

#### How to develop a **Patient Care Coordination Note** In EPIC:

- This note is accessible and editable by anyone in the hospital
- If a record already has notes in it, you can just click on PCCN and type in
- If there is NO PCCN for a patient:
  - Go to “care teams”. This option may not pull up automatically. You may have to “customize” your tabs. *(This option is usually used to CC other physicians on notes).* There is a link to PCCN through this tab.

The screenshot shows the EPIC Specialty Snapshot interface. The main content area displays a **Patient Care Coordination Note** for patient Gretchen L Oswald, MS, dated Monday, January 13, 2020, at 2:09 PM. The diagnosis is **Vascular Ehlers Danlos syndrome**. Under the heading **Emergency Situations**, there are three numbered items:

1. **CVS: aortic or arterial dissection**
2. **HOLLOW ORGAN RUPTURE: Bowel rupture is a COMMON complication of Vascular EDS.**
3. **Pulmonary: Spontaneous pneumothorax**

A concluding sentence states: **If there are urgent questions or concerns, please contact [Genetics Call pager \(667-239-0265\)](#), and that prompt imaging and consideration of the above problems needs to occur if patient presents urgently with symptoms that could be related to these situations.** The interface includes a left-hand navigation menu with options like Snapshot, Chart Review, and Demographics, and a top navigation bar with various system tools.



## Sample Notes for Emergency Situations

### Marfan Syndrome Emergencies

1. Cardiovascular: Extreme risk for aortic dissection or rupture. While risk is greatest at the aortic root, dissection often propagates into the descending aorta and isolated type B dissections are not uncommon.
2. Pulmonary: Risk for spontaneous pneumothorax

### Vascular Ehlers Danlos Syndrome Emergency Situations:

1. Stroke like presentations: Most common causes are carotid or vertebral dissection with partial or complete occlusion. In some instances these are secondary to aortic dissection with extension to the neck vessels.
2. Chest and back pain of sudden onset, with extension and/or hypotension:  
Cardiovascular: High risk of dissection or rupture of the aorta or the subclavian vessels with hemothorax or mediastinal bleeding. This can occur without any prior history of aneurysm.  
Carotid cavernous sinus fistula
3. Sudden eye pain, decreasing vision, protrusion of the globe and restriction of globe movement: carotid-cavernous sinus fistula. This is an ocular emergency and will lead to blindness if not treated.
4. Sudden onset and continuing abdominal pain:  
Vascular: dissection or rupture of aorta or other artery within the abdominal region. This can occur without prior history of aneurysm.  
Gastrointestinal: Spontaneous bowel perforation is common, often involving the sigmoid colon.
5. Abdominal pain and hypotension during pregnancy: Uterine rupture during later stages of pregnancy, uterine hemorrhage. See also concerns for abdominal vessel rupture or dissection
6. Chest pain and difficulty breathing or shortness of breath: : Risk for spontaneous pneumothorax

### AVOID INVASIVE PROCEDURES

1. Avoid arterial catheterization unless absolutely necessary.
2. Release IV contrast slowly.
3. Avoid endoscopy procedures unless absolutely necessary. If performed, use the smallest device and pressure possible and engage the most experienced practitioner.
4. Use ultrasound guidance and the most experienced practitioner for essential placement of central lines.
5. Elective surgical procedures should not be performed casually, and should ideally occur in a tertiary care center and in any setting with vascular surgery backup.
6. IV contrast agents, when indicated, should be administered slowly.

### Loeys-Dietz Syndrome Emergency Situations

1. Cardiovascular: Extreme risk for aortic dissection or rupture. While risk is greatest at the aortic root, dissection often propagates into the descending aorta and isolated type B dissections are not uncommon. Dissection or rupture can occur along the entire arterial tree.
2. Pulmonary: Risk for spontaneous pneumothorax
3. Neurologic: Risk for cervical spine dislocation causing spinal cord imaging
4. Systemic: Risk for life-threatening allergic reactions. Epinephrine should be used if needed for management of cardiovascular or respiratory compromise.