When you think of VHL you must think about ten possible locations

**Initial Evaluation**
- Making or confirming the diagnosis
- Family history
- Prior consultations
- Laboratory Studies
- Radiologic studies
- Physical findings
- Symptoms

- Eye/retinal examination
- MRI scan of abdomen
- Physical examination
- Laboratory tests for metanephrines
- MRI scan of brain and spine

**Initial Consultation**

- Complete workup by our multi-discipline team
- History and family tree
- Genetic counseling and testing to confirm diagnosis
  - Insurance issues
  - Impact on other health related issues
  - Impact on family members
- GU evaluation with a physical exam and imaging studies
- GI evaluation with a physical exam and imaging studies
- Neuro-surgical assessment with brain and spinal cord examination and radiologic studies
- Endocrine evaluation including history and physical exam with laboratory studies and imaging studies
- Ophthalmology evaluation with a thorough exam
When you think of VHL you must think about ten possible locations

- If you have a family history
  - you need only a single VHL associated tumor.

- Without a family history you need at least two VHL associated tumors to make a clinical diagnosis or:
  - One hemangioblastoma
  - PLUS
  - Visceral tumors
When you think of VHL you must think about ten possible locations.
When you think of VHL you must think about ten possible locations:

1. Brain / Spinal Hemangioendothelioma
2. Retina Hemangioendothelioma
3. Endolymphatic Sac Tumor
4. Pheochromocytoma, Paraganglioma
5. Benign, Asymptomatic Lung Lesion
6. Pancreatic Cyst / Tumor / Cancer
7. Kidney Cyst, Renal Cell Carcinoma
8. Cystadenoma [for both M and F]

International Plaza
Devoted clinical space for our patients
Easy access and parking
Full laboratory and radiologic services

Screening:
- Eye/retinal examination: Annually
- Ultrasound alternating with MRI: scan of abdomen
- Physical examination: Annually
- Laboratory tests for metanephrines: Annually
- MRI scan of brain and spine: Every other year

The Moffitt Cancer Center
VHL clinics
- International Plaza
  - Central location
  - Easy access and parking
  - Full laboratory and radiologic services
  - Devoted clinical space for our VHL patients

Average age of onset (age range of diagnosis), Years
Frequency in Patients, %

<table>
<thead>
<tr>
<th>Location</th>
<th>Average Age of Onset</th>
<th>Frequency in Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Nervous System</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain / Spinal Hemangioendothelioma</td>
<td>26 (1-44)</td>
<td>26-45</td>
</tr>
<tr>
<td>Retina Hemangioendothelioma</td>
<td>22 (12-60)</td>
<td>10-80</td>
</tr>
<tr>
<td>Endolymphatic Sac Tumor</td>
<td>33 (3-78)</td>
<td>6-72</td>
</tr>
<tr>
<td>Pheochromocytoma, Paraganglioma</td>
<td>22 (12-46)</td>
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This is what we do at the Moffitt Cancer Center VHL Clinic

Summary

- Thorough and extensive initial evaluation
- Initial diagnostic criteria is applied utilizing historic, radiologic, physical and genetic data
- Baseline and surveillance monitoring
- Multidisciplinary approach to care
- Specialists trained in the nuances of VHL

Total care of our VHL patients in a supportive well-coordinated manner