Suggested Referral Criteria for VHL

These are criteria used to REFER patients for a VHL workup and genetic testing. These are NOT criteria for clinical diagnosis of VHL.

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1. Any blood relative of an individual diagnosed with VHL disease
2. Any individual with:
   - Hemangioblastoma (HB)
   - Clear cell renal carcinoma (RCC)
   - Pheochromocytoma (PHE)
   - Endolymphatic sac tumor (ELST)
   - Epididymal or adnexal papillary cystadenoma
   - Pancreatic serous cystadenomas or pancreatic neuroendocrine tumors.
3. Any individual with ONE or more of the following:
   - CNS hemangioblastoma
   - Pheochromocytoma or paraganglioma
   - Endolymphatic sac tumor (ELST)
   - Epidiydmal papillary cystadenoma
4. Any individual with Clear cell renal carcinoma (RCC) diagnosed at a < 40 year old patient Bilateral and/or multiple clear cell RCC
   - >1 pancreatic serous cystadenoma
   - >1 pancreatic neuroendocrine tumor
   - Multiple pancreatic cysts + any VHL-associated lesion