PHEOCHROMOCYTOMA RESEARCH SUPPORT ORGANIZATION (PRESSOR) PATIENT DATA COLLECTION SHEET

1. INSTITUTIONAL DATA		
Center	City/State/Country	
P.I.	Tel:	Email:
Protocol	Written informed consent ☐ Yes ☐ No	

2. PATIENT DEMOGRAPHICS		
I.D. (encoded)	D.O.B.(mo/day/yr)	☐ female ☐ male

3. DISEASE PRESENTATION
☐ diagnosis based primarily on signs and symptoms
☐ incidental finding on imaging for unrelated medical condition
☐ routine screening due to family history or known mutation
☐ routine screening due to previous pheochromocytoma
☐ other (describe)

4. SIGNS AND SYMPTOMS		
Blood pressure and heart rate (seated)	Date recorded (mo/day/yr)	
☐ normotension ☐ sustained hypertension	B.P.	H.R.
☐ paroxysmal or episodic hypertension	B.P. (high)	B.P. (low)
Any problems with episodes of low BP or postural hypotension? ☐ Yes ☐ No		
Date any disturbance of BP first noted (approx. mo/yr):		

Symptoms		Frequency	Duration
Headaches	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Sweatiness	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Palpitations	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Panic/Anxiety	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Dizziness	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Pallor	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Flushing	☐Yes ☐No	☐daily ☐weekly ☐monthly	☐ 1–30min ☐ >30min
Other	☐Yes ☐No	Describe:	
Date symptoms first noted (approx. mo/yr):			

5. GENETICS AND HEREDITARY PREDISPOSITION

Medical /family history suggests hereditary syndrome ☐ Yes ☐ No

If yes, what syndrome?

☐ VHL ☐ MEN 2 ☐ Familial paraganglioma ☐ Von Recklinghausen ☐ Not clear

and what is the evidence?_____.

_____.

_____.

_____.

Germline mutation analysis has been performed ☐ Yes ☐ No

If yes, which genes were tested? ☐ VHL ☐ RET ☐ SDHB ☐ SDHD ☐ NF1

Mutation Detected ☐ Yes ☐ No	If yes, specify ☐ VHL ☐ RET ☐ SDHB ☐ SDHD ☐ NF1 Codon: _____. Nucleotide change: _____.

Other test? (e.g., protein–specify)

6. MEDICAL HISTORY

Has this patient had a previously diagnosed pheochromocytoma or paraganglioma? ☐ Yes ☐ No	If yes, specify location(s) and dimensions of previous tumor(s) and date(s) of resection (attach biochem. results if available). Location(s):_____. Dimensions (cm): _____. Date(s) of resection (mo/day/yr):_____.
Other current tumors? ☐ Yes ☐ No	If yes, describe:
Other medical conditions? ☐ Yes ☐ No	If yes, describe:
Previous tumors or medical conditions? ☐ Yes ☐ No	If yes, describe:

List current prescribed & over–the–counter medications:_____.

_____.

_____.

7. BIOCHEMICAL TEST RESULTS

Urine tests ———>		Catecholamines			Frac. Metanephrines			VMA
Units———————>		☐ µg/day ☐ µmol/day			☐ µg/day ☐ µmol/day			
Analyte———————>		NE	EPI	DA	NMN	MN	MTY	VMA
Reference range—>								
Test 1	Date:							
Test 2	Date:							
Test 3	Date:							
Blood tests———>		Catecholamines			Frac. Metanephrines			CGA
Units———————>		☐ ng/L ☐ nmol/L			☐ ng/L ☐ nmol/L			
Analyte———————>		NE	EPI	DA	NMN	MN	MTY	CGA
Reference range—>								
Test 1	Date:							
Test 2	Date:							
Test 3	Date:							

Was a clonidine suppression test performed? ☐ Yes ☐ No If yes, attach results

8. RADIOLOGY AND NUCLEAR MEDICINE

Imaging modality		Date (mo/day/yr)	Tumor(s) located
☐ CT ☐ abdomen ☐ whole body			☐ Yes ☐ No
☐ MRI ☐ abdomen ☐ whole body			☐ Yes ☐ No
☐ ^{131}I–MIBG ☐ ^{123}I–MIBG			☐ Yes ☐ No
☐ Octreotide			☐ Yes ☐ No
☐ PET	Agent:		☐ Yes ☐ No
☐ Other	Describe:		☐ Yes ☐ No

Tumor location and size	Multiple tumors: ☐ Yes ☐ No	If yes, specify no:

Abdominal locations	Size (cm)	Thoracic or head & neck locations	Size (cm)
☐ Adrenal – right ☐ Adrenal – left ☐ Periarotic/pericaval ☐ Organ of Zuckerkandl ☐ Retroperitoneal ☐ Bladder ☐ Other (specify)		☐ Aorticopulmonary/mediastinal ☐ Cardiac/pericardial ☐ Pulmonary parenchyma ☐ Carotid body ☐ Vagus nerve ☐ Jugular ☐ Other (specify)	

Evidence of malignancy ☐ Yes ☐ No	If yes, date diagnosed (mth/yr)

If yes, location of lesions:	☐ Bone ☐ Liver ☐ Lungs ☐ Lymph ☐ Other(specify)				
Approx. no of lesions:					

9. SURGICAL PATHOLOGY

Date of surgery (mo/day/yr)	**Dimensions (cm x cm x cm)**	**Weight (gm)**
☐ Unilateral adrenalectomy ☐ right ☐ left ☐ Bilateral adrenalectomy ☐ Solitary extra-adrenal (specify location below) ☐ Multifocal extra-adrenal (specify location below) ☐ Metastatic lesion(s) (specify location below)		

☐ Full resection ☐ Partial resection	Malignancy confirmed ☐ Yes ☐ No

Location of extra-adrenal tumor(s) or metastatic lesion(s)

Immunohistochemistry	☐Chomogranin A ☐S100 ☐others (specify)

10. PATIENT FOLLOW-UP

Date of first follow-up (mo/day/yr)	

Is there evidence of residual/continuing disease? ☐ Yes ☐ No

Detail evidence for or against residual/continuing disease (e.g., biochemical test results)

Dates of subsequent follow-ups (mo/day/yr)	

Is there evidence of residual/continuing disease? ☐ Yes ☐ No

Detail evidence for or against residual/continuing disease (e.g., biochemical test results)