SDH RESEARCH TESTING - CLINICAL FEATURES CHECKLIST

To meet criteria for this study, participants must have a personal history of at least one paraganglioma or pheochromocytoma confirmed by pathology. We will also accept participants with a known *SDH* mutation or variant of uncertain significance. Please complete this form and attach available records. Contact the study coordinator at (216) 445-6798 or pgl@ccf.org with questions.

Patient Name		**DOB**		Date		☐ Male ☐ Female

Have the following tests been performed?	If yes, please note results below and attach copy of clinical results:
Clinical *SDHB* testing	☐ no ☐ yes
Clinical *SDHC* testing	☐ no ☐ yes
Clinical *SDHD* testing	☐ no ☐ yes
Clinical *VHL* testing	☐ no ☐ yes
Clinical *RET* testing	☐ no ☐ yes
Does the patient have a family history of Paraganglioma/Pheochromocytoma?	☐ no ☐ yes

Paraganglioma/Pheochromocytoma Tumors

Complete the following information for each paraganglioma/pheochromocytoma tumor in patient's personal history. Attach copies of available pathology, imaging, and laboratory results. If necessary, print additional pages for patients with 4 or more tumors.

**Bilateral tumors should be described separately as 1st Tumor and 2nd Tumor*

First Tumor: Age of onset ____ Date of Diagnosis: ____

Location:
☐ Carotid ☐ Thorax/chest ☐ Other: ____
☐ Jugulotympanic ☐ Abdominal (extra-adrenal)
☐ Vagal ☐ Pelvic
☐ Other head/neck site ☐ Adrenal ☐ Unknown location

Laterality*: ☐ Right ☐ Left ☐ Unknown ☐ N/A

Neoplasm: ☐ Benign ☐ Malignant ☐ Unknown

Size (list units): ____ ☐ Unknown

Determined by:
☐ CT ☐ MRI
☐ Pathology ☐ Other: ____

Symptoms at diagnosis:

Hypertension	☐ no	☐ yes	☐ unk
Tachycardia	☐ no	☐ yes	☐ unk
Sweating	☐ no	☐ yes	☐ unk
Headache	☐ no	☐ yes	☐ unk
Peak Blood Pressure: ____			☐ unk

Catecholamine/metanephrine analysis:
☐ Normal ☐ Not done
☐ Abnormal ☐ Results unknown
List results or attach records:

Second Tumor: Age of onset ____ Date of Diagnosis: ____ ☐ N/A

Location:
☐ Carotid ☐ Thorax/chest ☐ Other: ____
☐ Jugulotympanic ☐ Abdominal (extra-adrenal)
☐ Vagal ☐ Pelvic
☐ Other head/neck site ☐ Adrenal ☐ Unknown location

Laterality*: ☐ Right ☐ Left ☐ Unknown ☐ N/A

Neoplasm: ☐ Benign ☐ Malignant ☐ Unknown

Size (list units): ____ ☐ Unknown

Determined by:
☐ CT ☐ MRI
☐ Pathology ☐ Other: ____

Symptoms at diagnosis:

Hypertension	☐ no	☐ yes	☐ unk
Tachycardia	☐ no	☐ yes	☐ unk
Sweating	☐ no	☐ yes	☐ unk
Headache	☐ no	☐ yes	☐ unk
Peak Blood Pressure: ____			☐ unk

Catecholamine/metanephrine analysis:
☐ Normal ☐ Not done
☐ Abnormal ☐ Results unknown
List values or attach records:

Third Tumor: Age of onset ____ Date of Diagnosis: ____ ☐ N/A

Location:
☐ Carotid ☐ Thorax/chest ☐ Other: ____
☐ Jugulotympanic ☐ Abdominal (extra-adrenal)
☐ Vagal ☐ Pelvic
☐ Other head/neck site ☐ Adrenal ☐ Unknown location

Laterality*: ☐ Right ☐ Left ☐ Unknown ☐ N/A

Neoplasm: ☐ Benign ☐ Malignant ☐ Unknown

Size (list units): ____ ☐ Unknown

Determined by:
☐ CT ☐ MRI
☐ Pathology ☐ Other: ____

Symptoms at diagnosis:

Hypertension	☐ no	☐ yes	☐ unk
Tachycardia	☐ no	☐ yes	☐ unk
Sweating	☐ no	☐ yes	☐ unk
Headache	☐ no	☐ yes	☐ unk
Peak Blood Pressure: ____			☐ unk

Catecholamine/metanephrine analysis:
☐ Normal ☐ Not done
☐ Abnormal ☐ Results unknown
List values or attach records:

Other Cancer/Tumor History

Please note any other cancer or tumor diagnoses in patient, including age of onset and pathology description. If available, please include confirmatory records:

The Cleveland Clinic
IRB 8458: Molecular Mechanisms Involved in Cancer Predisposition

Subject Consent to Contact Form

I have reviewed the information provided about the research study and I am interested in learning more. A representative from The Genomic Medicine Institute has permission to contact me regarding study participation.

Phone number: (_____)_____ Preferred days/times: _____

Alternate number: (_____)_____ Preferred days/times: _____

Today's date: _____

Your signature: _____

Print your name: _____

If you are consenting on behalf of a child (under 18 years old), please print the child's name: _____

Participant's date of birth: _____

Contact information for health care provider facilitating study participation:

Name: _____ Title: _____

Institution: _____

E-mail: _____ Phone number: (_____) _____

Please mail this form to:

The Cleveland Clinic
Genomic Medicine Institute
9500 Euclid Avenue, R4
Cleveland, OH 44195

OR

FAX to:

FAX #: (216) 636-0009
Attn: Beth Crouser, MBA

Cleveland Clinic

AUTHORIZATION TO DISCLOSE HEALTH INFORMATION TO CLEVELAND CLINIC

1. Patient Information:			
Name *(First, Middle, Last)*		Cleveland Clinic Medical Record # if known:	
Current Address		City State Zip	
Last 4 Digits of Social Security # N/A	Email	Phone Number ( )	Date of Birth / /

2. Release Information From:		3. Release Information To: CLEVELAND CLINIC	
Facility/Provider:		Name of Recipient: Beth Crouser, MBA Facility and/or Mail Code: Genomic Medicine Institute / R4	
Address	City/State Zip	Address 9500 Euclid Avenue	City/State Zip Cleveland, OH 44195
Phone Number ( )		Phone Number (216) 445-5850	Fax Number (216) 636-0009
		Select one: ☒ Paper ☒ Secure electronic delivery (If secure delivery, provide email): crouseb2@ccf.org	

Purpose for Disclosure: ☐ **Continuity of Care** ☒ **Other (please indicate)** Referral to research study
(Purpose for disclosure must be completed prior to processing.)

Dates of service to release (FROM): _____ **(TO):** Present

☐ Office Visits	☐ History & Physical	☒ Research paperwork including medical records
☐ Emergency Department Reports	☐ Other _____	☐ _____
☐ Discharge Summary	☐ _____	☐ _____
☐ Operative Reports	☐ _____	☐ _____

I, the undersigned, authorize the above named sending Facility/Provider as described in Section 2 to release health information as indicated/described above. I understand and acknowledge that the requested health information may contain information regarding physical and mental illness, HIV test results or diagnosis, treatment of AIDS/AIDS-related conditions, and/or alcohol/drug abuse. **This authorization does not include permission to release outpatient Psychotherapy Notes as defined below.* Release of Psychotherapy Notes requires a separate authorization.**

This authorization and consent will expire one year from the date of authorization written below, unless revoked by me (or my legal representative) through written notice presented to above named Facility/Provider as described in Section 2. Any revocation will not apply to information that has already been released in response to this authorization. I understand that treatment, payment, enrollment, or eligibility for benefits will not be based on whether or not I sign this authorization.

I understand that the sender of my health information may charge for the service of disclosing medical information and I am responsible for inquiring about these potential charges.

If Authorization is not complete, signed and dated, it may be returned and result in my information not being released until completed.

_____ / _____ ____/____/____

Signature of Patient/Patient's Personal Representative *Printed Name* *Date Signed*

_____

Relationship, if not Patient

**Psychotherapy Notes are defined as notes that document private, joint, group, or family counseling sessions that are separated from the rest of a patient's medical records.*

Submit completed request to the Cleveland Clinic Facility/Mailcode identified in Section 3 above.

NOTICE: If you send health information to Cleveland Clinic via email, please know that your message may be sent in an unencrypted email. An unencrypted email means there is a risk that the information in the email and any attachments could potentially be read by a third party when it is sent through the Internet.