IDR FORM
Susac Syndrome International Disease Registry (IDR)

Patient IDR Code: _____

This form is designed for a patient's physician to complete (with or without the help of the patient or a family member). The Form may be completed by hand, or electronically, and may be mailed, FAXed (216-636-3002), or Scanned-and-Emailed-as-an-Attachment, to Dr. Rennebohm at: rennebr@ccf.org

The goal of this form is to collect very basic (but very important) information (e.g. age, gender, country of residence, and ethnicity) on as many patients as possible, from around the world---to find out how many patients there are, world-wide, and whether Susac syndrome is more common in some countries or ethnic groups than in others.

Please see the IDR <u>Physician and Patient Information Sheet</u> for more details about the IDR project.

Only the information below will be entered into the International Disease Registry (IDR). <u>No patient identifying information will be entered into the IDR.</u> Your information will be identified only by your anonymous Patient IDR Code. Only the physician who is enrolling the patient in the IDR knows the name associated with the Patient IDR Code. Dr. Rennebohm will know the physician associated with the Patient IDR Code, but will not know the name of the patient (unless Dr. Rennebohm is the enrolling physician for the patient).

Gender: **Male_____**   **Female_____**

Patient's Country of Residence when he/she developed Susac syndrome:

_____ **(Enter Country)**

Patient's Home Country (The country the patient views as his/her Home country):

_____ **(Enter Home Country)**

If you were living in the United States of America (USA) when you developed Susac syndrome, what STATE were you living in when you developed Susac syndrome?

_____ **(Enter State)**

Susac syndrome can affect the BRAIN, the EYE, the INNER EAR, or any combination of these. So, Susac syndrome has three potential components---a brain component, an eye component, and an inner ear component. Most patients eventually experience at least 2 of these components.

BRAIN component: Has the patient experienced any symptoms of Susac involvement of the brain (e.g. cognitive dysfunction, headache, memory loss, confusion, or slow thought processing)? If the patient has had MRI abnormalities in their brain, but has never convincingly had any brain symptoms, then check "No" as your answer.

         Check only one of the answers below:

                 ____Yes, the patient has experienced symptoms of <u>Brain</u> involvement

                 ____No, the patient has not experienced symptoms of <u>Brain</u> involvement

                 ____We are Unsure

EYE component: Has the patient experienced Susac involvement of the eyes/retina (e.g. scotoma, a dark spot in their vision, BRAO, or Susac fluorescein angiography abnormalities)?

_____Yes, the patient has experienced Susac <u>Eye</u> involvement

_____No, the patient has not experienced Susac <u>Eye</u> involvement

_____We are Unsure

INNER EAR component: Has the patient experienced Susac involvement of the inner ear (e.g. hearing loss, tinnitus, or vertigo)?

_____Yes, the patient has experienced Susac inner <u>Ear</u> involvement

_____No, the patient has not experienced Susac inner <u>Ear</u> involvement

_____We are Unsure

First Symptom(s): What was/were the VERY FIRST SYMPTOM(s) of the patient's Susac syndrome--- brain symptoms, eye symptoms, ear symptoms, or a combination of these? By "very first" symptom(s), we mean the symptom or symptoms that appeared during the FIRST WEEK of the patient's Susac syndrome.

Check the type of symptoms that appeared <u>during the first week</u> of the Susac syndrome. (You may check more than one, if more than one type of symptom was present during the first week.)

_____Brain symptom(s)

_____Eye symptom(s)

_____Inner Ear symptom(s)

_____We are Unsure

Which of the three types of Susac symptoms appeared <u>within 4 weeks</u> after appearance of the first symptom(s)? (Include the first type of symptom that appeared)

You may check more than one.

_____Brain symptom(s)

_____Eye symptom(s)

_____Inner Ear symptom(s)

_____We are Unsure

Patient's Age (in yrs and mos) when his/her first symptom(s) of Susac syndrome appeared (e.g. 32 years, 4 months):

Enter your best estimate, or if you are unsure, you may enter "Unsure."

_____ Years   Months _____   Unsure _____

Patient's Age (yrs and mos) when it was first concluded that his/her diagnosis was Susac syndrome (e.g. 32 years 5 months):

Enter your best estimate, or if you are unsure, you may enter "Unsure."

_____ Years   Months _____   Unsure _____

MRI Abnormalities: Has one or more of the patient's MRIs shown abnormalities in the corpus callosum? (Please consider sending us a CD containing the MRI studies.)

_____ Yes

_____ No

_____ We are Unsure

BRAO: Has the patient ever had a BRAO (Branch Retinal Artery Occlusion)?

_____ Yes

_____ No

_____ We are Unsure

Hearing Loss/Audiogram results: Check the boxes that indicate the type and extent of hearing loss the patient has had.

You may check more than one answer. Check all answers that apply. You may leave some answers unchecked.

_____The patient has had no hearing loss

_____The patient has hearing loss, but it is not due to my Susac syndrome

_____ The patient has had hearing loss due to Susac syndrome

_____Hearing loss in only one ear

_____Hearing loss in both ears

_____Low frequency hearing loss

_____High frequency hearing loss

_____We are unsure whether it is low or high frequency hearing loss

_____The patient wears a hearing aide (at least sometimes)

_____The patient has had a cochlear implant

Severity of Hearing Loss (in the most affected ear)

Select only one answer.

_____**Mild hearing loss (in the most affected ear)**

_____**Moderate hearing loss (in the most affected ear)**

_____**Severe hearing loss (in the most affected ear)**

ETHNICITY of patient's biological MOTHER:

Please note the list of ethnicities below. Enter as many of those ethnicities as apply. Also, you may enter mixtures, or an ethnicity/origin that is not on the list.

Ethnicity (Ethnicities) of Mother: _____

ETHNICITY of patient's biological FATHER:

Ethnicity (Ethnicities) of Father _____

Examples of ethnic groups

Africa---Caribbean:
- Arab: Egyptian, Moroccan, Tunisian, Algerian, other Arab
- African-American
- Black African: Ethiopian, Somalian, Kenyan, Tanzanian, Ghanaian, Nigerian, other black African
- Black Caribbean: Haitian, Jamaican, Barbadian, Cuban, Puerto Rican, other West Indian, other Caribbean

Middle East—Central-West Asian:
- Arab: Lebanese, Palestinian, Syrian, Jordanian, Iraqi,
- Israeli
- Central-West Asian: Armenian, Turkish, Kurdish, Persian, Afghan, Kazahkstanian, Uzbekistanian, Tajikistanian

Asian:
- Chinese: Chinese, Mongolian, Tibetan
- Japanese
- Korean
- Filipino
- South Asian: Bengali, Gujarati, Punjabi, Tamil, East Indian, Bangladeshi, Pakistani, Singhalese, Sri-Lankan
- Southeast Asian: Vietnamese, Cambodian, Laotian, Thai, Malay, Burmese, Indonesian
- Pacific Islander: Fijian, Polynesian, Hawaiian, other Pacific Islander

European:
- British Origin: English, Irish, Scottish, Welsh, other British
- Western European: Austrian, Belgian, Dutch (Netherlands), Flemish, German, Luxembourg, Swiss
- French Origin: French, French Canadian, Franco-Ontarian, Franco-Manitoban, Acadian
- Northern European: Norwegian, Swedish, Danish, Finnish
- Eastern European: Baltic origins, Belo-Russian, Czech, Slovak, Hungarian, Polish, Romanian, Russian, Ukrainian
- Southern European: Balkan origins, Cypriot, Greek, Italian, Maltese, Portuguese, Spanish

American:
- Aboriginal Inuit
- Aboriginal North American Indian   Band_____
- Latin American: Argentinean, Brazilian, Chilean, Colombian, Ecuadorian, Guatemalan, Hispanic, Mexican, Nicaraguan, Peruvian, Salvadoran, other Central and South American Latin

The patient has been notified that I am submitting this form to the IDR:

_____ **Yes**

The patient has been sent a copy of the Patient IDR Information Sheet:

_____ **Yes**

Date on which I am submitting this IDR Form:

MM _____   DD _____   YYYY _____

I have checked with the patient to determine if any other physicians have submitted an IDR Form on this patient: (Check only one)

_____ **None of the patient's other physicians has submitted an IDR form**

_____ **I have not checked, or am uncertain**

Additional Comments/Clarifications/Details regarding the patient's Susac syndrome: (Do not use any patient identifying information)