

HUNTINGTON STUDY GROUP

QUESTIONNAIRE FOR POTENTIAL NEW INVESTIGATORS

PLEASE TYPE OR PRINT ALL ANSWERS CLEARLY. If you prefer to receive/ return this questionnaire by e-mail, please contact Amy Ettaro at amy.ettaro@urmc.rochester.edu.

Date:

Name (and academic initials):

Title:

Address:

Phone:

Fax:

E-mail:

1. Explain in one paragraph the principal reason you wish to join the HSG.

2. What do you see as your role in the HSG?

3. Attach your CV with your cover letter.

4. Are you salaried by an institution? If so, please state the name of the institution and your title there.

Yes

No

Institution:

Title:

5. Are you a general neurologist or do you sub-specialize in neurology?

General Neurologist

Sub-specialize in Neurology

If so, what fields of neurology do you consider your sub-specialty?

Please list your sub-specialty organization memberships.

6. Are you a member of the Movement Disorder Society (MDS)?

Yes

No

If so, how long have you been a member?

7. What regional or national HD meeting(s) have you participated in the past 5 years?

8. Briefly describe your HD clinic:

a) Frequency of the clinic

b) Staff and their experience and interests

- c) Number of patients seen each clinic?
 - i) How many patients are < 21 years of age?
 - ii) How many patients are > 21 years of age?
- d) How many patients are at-risk by virtue of having (had) a parent with HD?
- e) How many patients have manifest HD?
- f) Do you participate in predictive testing?
- g) Do you reveal the actual CAGn to your patients?
- h) What is done to make the public aware of our clinic?

9. Estimate the percent of your total neurology patients that belong to an ethnic minority.

- African-American
- Hispanics
- Asians
- Native-Americans

What is the basis of your estimate? (Check (√) all that apply)

- An approximation off the top of your head
- A clinical database
- Sampling of past office visits or charts

10. Do you use rating scales for monitoring severity of HD?

- Yes
- No

If yes, which ones?

11. Estimate the number of UHDRS completed by you:

Cumulatively:

Monthly:

12. Name the geographically close HD research centers that might compete with HD subject enrollment in clinical trials.

13. Have you participated in any clinical trials in the past 5 years?

Yes No

If so, briefly describe them.

14. Have you ever been involved in NIH-funded clinical trials?

Yes No

If so, list them.

15. List your current and planned clinical trials.

CURRENT

PLANNED

16. How would you recruit subjects for an HD study (either symptomatic or asymptomatic)?

17. Have you completed a course on protection of human subjects that is required by NIH by October 2000?

Yes No

If yes, what is your certification number?

Please attach a copy of the certification.

***Please note* - Evidence of course completion will be required for credential approval for both investigator and coordinator.**

18. Is there currently a study coordinator employed by you?

Yes No

If yes, what is the coordinator's name?

What studies has the coordinator worked on?

Please attach coordinator's CV.

Has your coordinator completed a course on protection of human subjects?

Yes No

If yes, what is the certification number?

Please attach a copy of the certification.

19. What is the name and address of the Institutional Review Board (IRB) to which you submit clinical trials?

Name:

Address:

20. If you are selected to participate in the HSG, what institution will you use for the purposes of subcontracting for payments (must be academic or non-profit)? Please describe.

Institution Name:

Contact Name:

Phone number:

21. If you are selected to participate in the HSG, do you have an institutional resources for you and your coordinator to attend the annual HSG meetings without HSG financial support?

Yes

No

FOR HSG USE ONLY

Date Sent: _____

Date Received: _____