Section A: KEY IDENTIFYING INFORMATION

A1. Study Identification Number ___ ___ - ___ ___ ___ ___ ___ - ___

Replaced by blinded ID

blind_id	Blinded ID

A2. Acrostic Identifier ___ ___ ___ ___ ___

Removed to protect privacy

A3. Date of form completion ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

Replaced by age at form completion

comp_age	A3. <created var>Age at form completion, days

A4. Name of person completing form _____ ___ ___ ___
PRINT FULL NAME INITIALS

Removed to protect privacy

Section B: WITHDRAWAL OF STUDY DRUG

B1. Date last dose of study drug taken ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

Replaced by age at last dose of study drug

lstdos_age	B1. <created var>Age at last dose of study drug, days

B2. Last dosage of study drug administered ___ . ___ ___ mg bid

LSTDOSE	B2. Last dosage of study drug taken (mg bid)

B3. Phase of study drug administration UPTITRATION .....1 MAINTENANCE..... 2

DRUGPHSE	B3. Phase of study drug administration

B4. Last visit at which patient completed any study measures

BASELINE 0
STUDY VISIT 1 (Day 4) 1
STUDY VISIT 2 (Week 2) 2
STUDY VISIT 3 (Pre-Glenn) 3
STUDY VISIT 4 (Restart) 4
STUDY VISIT 5 (Age 10 mo.) 5

LSTVS203	B4. Last visit at which patient completed any study measures

Indication for permanent withdrawal of study drug (Answer ALL questions B5-B9)

B5. Anaphylactoid reaction YES ..... 1 NO 2

ANAPHYL	B5. Anaphylactoid reaction

B6. Serum creatinine >1.0 mg/dL after adjustment of study drug dose

YES ..... 1 NO 2

CREATGT1	B6. Serum creatinine > 1.0mg/dL after adjustment

B7. Study drug discontinued by study physician because of other adverse event(s)

YES ..... 1 NO .....2 **(B8)**

DCAE	B7. Study drug discontinued because of adverse event(s)

a. Specify other adverse event(s) _____

DCAE_S	B7a. Specify other adverse event

B8. Open label use of ACE inhibitor YES.....1 NO .....2 **(B9)**

ACEOPEN	B8. Open label use of ACE inhibitor

a. Date started open label use ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

Replaced by age at start of open label use

acestr_age	B8a. <created var>Age at start of open label use, days

b. ACE inhibitor code ___ ___ . ___ ___
(**See codes below**)

ACECODE	B8b. ACE inhibitor code

1. If code=13.99 (Other), specify: _____

ACEOTH	B8b1. Specify other

ACE inhibitors			
Code	**Generic (Trade) Name**	**Code**	**Generic (Trade) Name**
13.00	Converting enzyme inhibitor (unspecified)	13.07	Lisinopril (Prinivil, Zestril)
13.01	Benazepril (Lotensin)	13.08	Pentopril
13.02	Captopril (Capoten)	13.09	Perindopril (Aceon)
13.03	Cilarapril (Primaxin)	13.10	Quinapril (Accupril)
13.04	Enalapril (Vasotec)	13.11	Ramipril (Altace)
13.05	Enalaprilat (Vasotec)	13.12	Trandolapril (Mavik)
13.06	Fosinopril (Monopril)	13.99	Other converting enzyme inhibitor

B9. Other indication for discontinuation YES ..... 1 NO .....2 **(B10)**

DCOTH	B9. Other indication for discontinuation

a. Specify other indication _____

DCOTH_S	B9a. Specify other indication

B10. Comments _____

_____

COMMS203	B10. Comments