

**ERDHEIM CHESTER DISEASE: CLINICAL PHENOTYPE AND OUTCOME
A MULTICENTRE SURVEY
ECD001**

Information to send for study follows. Information can be sent on CD/DVD or as 'paper' copies. Please send all relevant information possible, especially that which is listed below:

1. Signed "Patient Consent Form" (See attached file, "ECD_Consent_for_Vaglio_Study" for form)..... _____
2. Detailed signed report from your treating doctor, summarizing your medical history, including ECD diagnostic criteria..... _____
3. Specialist reports where applicable. (e.g. cardiologist, dermatologist, pulmonologist, endocrinologist, etc.)..... _____
4. Most relevant imaging examinations (e.g, Bone Scintigram (bone scan), PET scans, CT scans, MRIs, Echocardiography, X-rays of the long bones,)
 - a. At diagnosis _____
 - b. At 6-12 months after diagnosis _____
 - c. Latest _____
5. Blood test results (including prolactin, testosterone, ADH, ACTH, TSH)
 - a. At diagnosis _____
 - b. At 6-12 months after diagnosis _____
 - c. Latest _____
6. Completed questionnaire form (See attached file, "Protocol_for_Vaglio_study", Appendix 2, for form)..... _____

Mail information to:

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