INTERNATIONAL REGISTRY OF WERNER SYNDROME AND OTHER PROGEROID SYNDROMES

UNIVERSITY OF WASHINGTON, DEPARTMENT OF PATHOLOGY
BOX 357470, SEATTLE, WA 98195-7470 USA
PHONE: (206) 543-5088 Fax: (206) 685-8356

Date of this report Yr_____Mo_____Day_____ *Date last physical exam Yr_____Mo_____Day_____*
Date of submission: blood specimen Yr_____Mo_____Day_____ *Skin Biopsy Yr_____Mo_____Day_____*
Registry form prepared by _____ *Tissue submitted by _____*

Patient Identification (Confidentiality assured)

Last name_____First_____Middle_____Phone_____
Address_____
Hospital no. or clinic registration no._____
Date of birth Yr____Mo.____Day____ Age at time of this report_____
Birth Place City_____ State or Providence_____Country_____
Sex____ Marital Status_____Occupation_____
Attending physician: Name_____ Phone_____
Address_____ FAX_____
_____
Other Physicians: Name_____ Phone_____
Address_____ FAX_____
Other Physicians: Name_____ Phone_____
Address_____ FAX _____
Pedigree Identification # when available
Has this patient been reported in the literature? _____ Cite reference:

Family History

Ethnic background
Pedigree (please draw the pedigree, if known) and attach
Parental consanguinity?_____ Type? (e.g. 1st cousin marriage) _____
Siblings with Werner's syndrome
Features of the disease in family
Children
Heights and ages of parents and siblings

Physical Appearance

Overall appearance of premature aging?
Short stature?_____ Height_____(cm) Weight_____(kilograms)
Birth height _____(cm) Birth weight_____(kilograms)
Pediatric and adolescent growth history (attach data or graphs, if available)
Thin limbs?
Pinched or bird-like facial features?
Loss of hair color?
Loss of hair?_____ scalp_____ other _____

Eyes

Were eyes examined by a slit lamp?
Cataracts? Left_____ Right_____ Bilateral_____ Age @ diagnosis_____ Age @ surgery_____
(Give anatomic description, if available)

Skin and Subcutaneous Tissue (give distribution)

Regional alterations in amounts of subcutaneous fat
Tight skin? _____ Atrophic skin? _____ Hypermelanosis? _____
Hyperkeratosis?_____ Soles of feet _____ Other_____
Ulcerations? (give localization)_____
Nail deformity? _____ Telangiectasia? _____ Cold Fingers? _____

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Last Name_____ First_____ Middle_____

Oral Cavity/neck/larynx
High pitched, squeaky or horse voice? (describe)
Irregular teeth? Laryngeal atrophy?
Thyroid enlargement?

Genitourinary
Age of menarche_____ Age of menopause_____
Amenorrhea?
Secondary sexual underdevelopment?
Atrophic testes?_____ (3 dimensional measurements):
Infertility?

Bones, joints, muscles
Flat feet? _____ Soft tissue calcification?_____
Osteosclerosis of phalanges of fingers _____ toes_____?
Osteoarthritis?
Muscle wasting?
Osteoporosis?
(cite relative involvement of vertebral vs long bones if known)

Cardiovascular
Murmurs?
Evidence of atherosclerosis/arteriosclerosis?
Peripheral vascular disease
Coronary artery disease
Medial calcinosis
Blood pressure

Neoplasms (benign and malignant)
(Give histopathologic diagnosis when available)

Neurological/Psychological
Hyperreflexia?
Mental disorders?
Cortical atrophy?
Other

Endocrine
Clinical dx of diabetes?
Type of diabetes
Other

X-ray findings

Laboratory results (please include a normal ranges)
Blood type
Glycosuria
Fasting blood glucose
Glucose tolerance test
Triglycerides
Cholesterol
High density lipoprotein_____ Low density lipoprotein_____
Liver function (specify tests)
24-hour urinary hyaluronic acid levels
Please note any other clinical abnormalities

Other valuable documents would include discharge hospital summaries, anatomic pathology and clinical lab reports, x-ray reports, and autopsy reports of siblings. Would this patient and patient's next-of-kin be likely to agree to autopsy examination? yes_____ no_____

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DIAGNOSTIC CRITERIA FOR WERNER SYNDROME

Last Name_____ First_____ Middle_____
Date of Analysis_____ Prepared by_____

Check cardinal signs and symptoms (onset over 10 years old)

____ 1. Cataracts (bilateral)
____ 2. Characteristic dermatological pathology (tight skin, atrophic skin, pigmentary alterations, ulceration, hyperkeratosis, regional subcutaneous atrophy) and characteristic facies ('bird' facies)
____ 3. Short stature
____**4. Parental consanguinity (3d cousin or greater) or affected sibling.
____ 5. Premature greying and/or thinning of scalp hair.
____ (6. Positive 24-hour urinary hyaluronic acid test, when available.)

Check further signs and symptoms

____ 1. Diabetes mellitus.
____ 2. Hypogonadism (secondary sexual underdevelopment, diminished fertility, testicular or ovarian atrophy).
____ 3. Osteoporosis.
____ 4. Osteosclerosis of distal phalanges of fingers and/or toes (x-ray diagnosis)
____ 5. Soft tissue calcification.
____ 6. Evidence of premature atherosclerosis (e.g. history of myocardial infarction).
____ 7. Mesenchymal neoplasms, rare neoplasms or multiple neoplasms.
____ 8. Voice changes (high pitched, squeaky or hoarse voice).
____ 9. Flat feet.

Definite: All the cardinal signs and two others.

Probable: The first three cardinal signs and any two others.

Possible: Either cataracts or dermatological alterations and any four others.

Exclusion: Onset of signs and symptoms before adolescence (except stature, since current data on pre-adolescent growth patterns are inadequate.)

** Type of consanguinity:
Number of affected sibs:

Registry No_____