

Patient Information	Primary Care	Diagnosis Collaborative care	Social Services
www.shwachman.nl https://rarecare.world	Growth retardation Recurrent infections (LOINC)	Guideline SDS (Orphanetcode; SNOMED, ATC e.a.)	Recurrent illness Fatigue, Short (ICF-CY; ISO 9999)

Stichting Shwachman syndroom Support Holland

New Diagnostics

Diagnosis
 Hurler syndrome
 PKU, Duchenne MD, FOP
 Shwachman Diamond Syndrome

ICD - 10
Orphacode
OMIM
SNOMED -CT
DCOM

Sign primary care
 Heelstick screening
 Hearing screening
 Growth; Development

Guideline
 Collaborative Health Care



New Therapeutics

ISO 3166-1
HL7/ FHIR

ATC
ICF
ISO9999



Registry
 Data collection with systematically organised computer processable collection medial terms

Guideline
 Social services and rehabilitation

