

# Supporting Shwachman Diamond Syndrome families with a multifunctional portal and personal health record

Liesbeth Siderius , Shwachman Diamond Syndrome Support Holland, the Netherlands  
 John Dodge, Shwachman-Diamond Support, UK

## Introduction

- 2009 needs of individuals with Shwachman Diamond Syndrome (SDS) collected
- increase knowledge recognition of the features and care coordination / co management wanted
- need guideline with accurate and harmonized care outcome measures
- 2011 draft guideline- on SDS features, diagnosis, treatment and monitoring has been published, include first examples of such follow up indicators
- technology can support consistent application of guidelines
- Coordinated Care Model : connects family with care providers by internet technology

## Model

Shwachman Diamond Syndrome Support Holland has developed a model for continuous integrated care and self management. In fact it will be an implementation of the internationally accepted chronic care model. Using the Medical Home Portal as example, the support group defined a two-layered portal design. The first layer holds publicly accessible information, such as on disease and disease characteristics. Defined health indicators can be collected by the person with SDS, and decided to feed anonymously into data registries. A personal health record – based on international standard IT codes- will be a key component here. This provides options for evaluating new diagnostic tests and procedures and new therapies.

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

