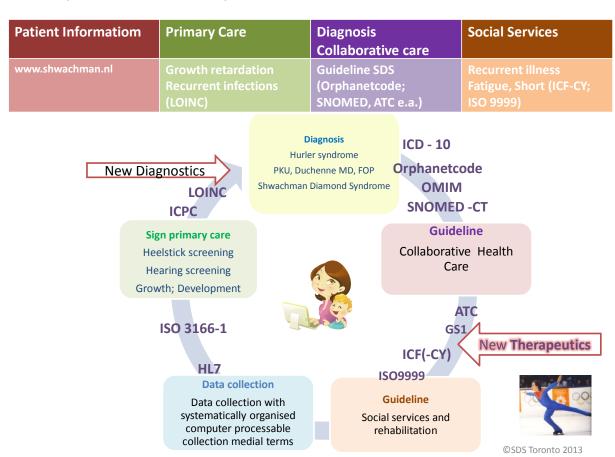
Supporting Shwachman Diamond Syndrome families with a multifunctional portal and personal health record

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.



7th International Congress on Shwachman Diamond Syndrome, Toronto, Canada, November 2013