"Een PGO voor iedereen“

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16e HL7 NEDERLAND WORKING GROUP MEETING, VIRTUEEL
4 november 2021

Introductie

Shwachman Diamond Co management
Rare Disease Interoperable Model

(Internationale) Samenwerking
VWS project Rare Care World

Med Mij en Europese kinderartsen
HL 7 en het PGO

Global Child Health
- Sustainable Development Goals
- Universal Health Coverage

International Medical Guideline

Shwachman Diamond Syndrome, 2011

Table 1. Clinical and molecular diagnostic criteria

Stichting Shwachman syndroom Support Holland

Diagnostic criteria

Clinical diagnosis:

Fulfill the combined presence of hematological cytopenia of any given lineage (most often neutropenia) and exocrine pancreas dysfunction

Hematologic abnormalities may include:

a. Neutropenia <1.5 x 109/L on at least 2 occasions over at least 3 months

b. Hypoproductive cytopenia detected on 2 occasions over at least 3 months

Tests that support the diagnosis but require corroboration:

a. Persistent elevation of hemoglobin F (on at least 2 occasions over at least 3 months apart)

b. Persistent red blood cell macrocytosis (on at least 2 occasions over at least 3 months apart), not caused by other etiologies such as hemolysis or a nutritional deficiency

Pancreatic dysfunction may be diagnosed by the following:

a. Reduced levels of pancreatic enzymes adjusted to age [fecal elastase, serum trypsinogen, serum (iso)amylase, serum lipase]

Tests that support the diagnosis but require corroboration:

a. Abnormal 72 hr fecal fat analysis

Dror Y, Donadieu J, Koglmeier J, Dodge J, Toiviainen-Salo S, Makitie O, Kerr E, Zeidler C, Shimamura A, Shah N, Cipolli M, Kuijpers T, Durie P, Rommens J, Siderius L, Liu JM. Draft consensus guidelines for diagnosis and treatment of Shwachman-Diamond syndrome. Ann N Y Acad Sci. 2011 Dec;1242:40-55. doi: 10.1111/j.1749-6632.2011.06349.x. PMID: 22191555.

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

HPO

LOINC

ICPC

Sign primary care

Heelstick screening

Hearing screening

Growth; Development

Guideline

Collaborative Health Care

Interoperable data model

ISO 3166-1

HL7/ FHIR

ATC

New Therapeutics

ICF

ISO9999

Registry

Data collection with systematically organised computer processable collection medial terms

Guideline

Social services and rehabilitation

(Internationale) Samenwerking: Rare Care . World

Subsidie VWS 2017-2018

Building the Rare Disease

knowledge and information ecosystem

rarecare.world

Thalassemia, Sri Lanka, 2018 SEARCH

OSCAR Nederland

Find and share knowledge about

Rare diseases all over the world

ATC

- L01XX05 Hydroxycarbamide (Hydroxyurea) (1)
- V03AC01 Deferoxamine (1)
- V03AC02 Deferipron (1)
- V03AC03 Deferasirox (1)

ICD

- D57 Sickle-cell disorders (1)

ICPC Reference

- B78.01 Thalassemia (1)
- B87 Splenomegaly (1)

LOINC

- 718-7 Hemoglobin in blood (1)
- 20567-4 Ferritin in Serum or Plasma (1)
- 46740-7 Hemoglobin disorders newborn screen interpretation (1)
- 53857-9 Hemoglobin F (1)

fractures or vertebral deformities. **Thalassemia** major or Beta **Thalassemia** ...
Rare Condition
Thalassemia major or Beta Thalassemia

Large spleen

Feature

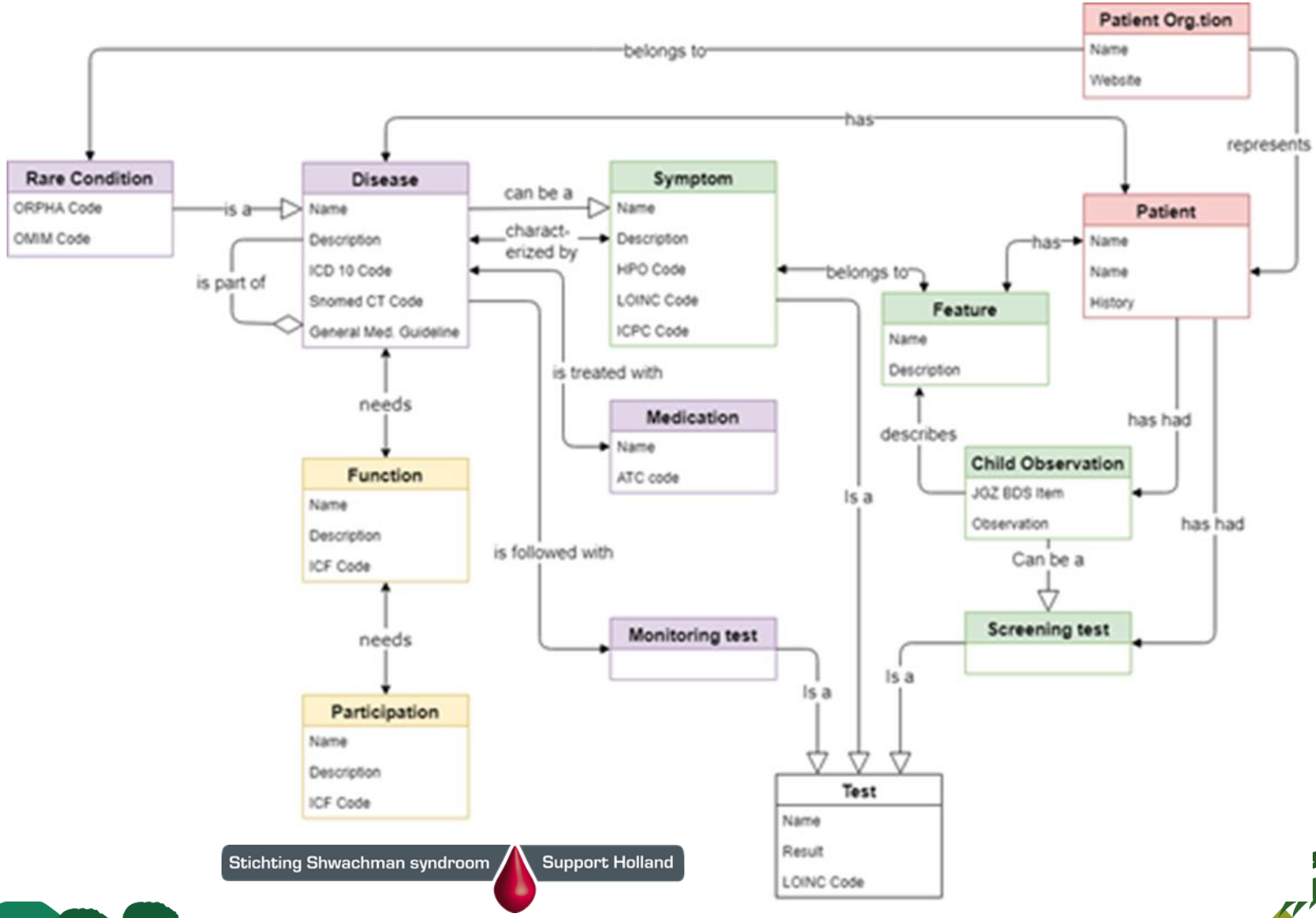
... costal margin. A large spleen is a feature of for example **Thalassemia** Infections Nieman Pick disease Gaucher disease Splenomegaly Splenomegaly in **thalassemia** **Thalassemia** major or Beta **Thalassemia** ...
Rare Condition
Thalassemia major or Beta Thalassemia
Symptom
Splenomegaly in thalassemia
Abnormality
Splenomegaly

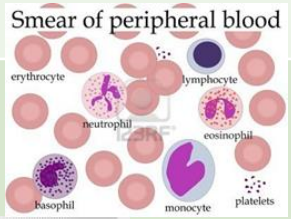
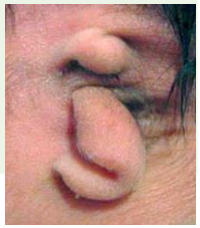
Carrier screening thalassemia

Symptom

... Carrier screening **thalassemia** Related family members with elevated HbA2 In carrier screening for the classical beta-**thalassemia** trait, the hallmark is the presence of an ... 2 (α 2 δ 2). Another way of identifying people with **thalassemia** major is neonatal screening. Neonatal screening ...
Rare Condition
Thalassemia major or Beta Thalassemia
Disease

Unified Modeling Language (UML)



Codification	Meaning
ICD & Orpha code	International Code of Diseases / Orphanet code
ICF (-CY) 	The *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)* is a derived version of the *International Classification of Functioning, Disability and Health* (ICF, WHO, 2001) designed to record characteristics of the developing child and the influence of environments surrounding the child .
LOINC 	A universal code system for tests, measurements, and observations.
ATC 	The purpose of the ATC/DDD system is to serve as a tool for drug utilization research in order to improve quality of drug use.
ISO 9999 	ISO 9999:2011 establishes a classification of assistive products, especially produced or generally available, for persons with disability.
HPO 	The Human Phenotype Ontology (HPO) provides a standardized vocabulary of phenotypic abnormalities encountered in human disease.

World Health Organization

LOINC

The international standard for identifying health measurements, observations, and documents.

Interoperable codes in care

LocalCode^LocalName^CodeSystem | LOINCcode^LOINCname^CodeSystem

OBX|2|NM|123^WBC^HSP_A^26464-8^Leukocytes [#/volume] in Blood^LN||10.8|K/MM3|||||F|
OBX|3|NM|234^RBC^HSP_A^26453-1^Erythrocytes [#/volume] in Blood^LN||4.82|MIL/MM3|||||F|
OBX|4|NM|345^HGB^HSP_A^718-7^Hemoglobin [Mass/volume] in Blood^LN||15.2|GM/DL|||||F|
OBX|5|NM|456^HCT^HSP_A^20570-8^Hematocrit [Volume Fraction] of Blood^LN||45|%|||||||F|

Notice how the result value and units have their own places in the message

Data type of result (OBX-5) is a coded element

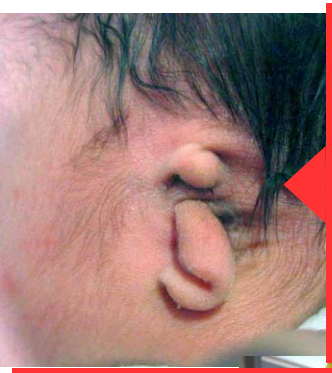
This code is from LOINC

This code is from SNOMED

OBX||CE|57131-5^Newborn conditions with pos markers^LN|7573000^PKU^SCT

Code identifying this observation (what are these results? Conditions identified by newborn screening)

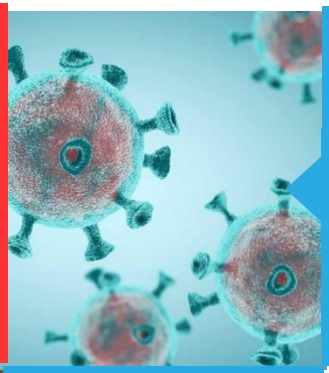
Code identifying the result (Phenylketonuria)



Goldenhar s
Abnormal ear

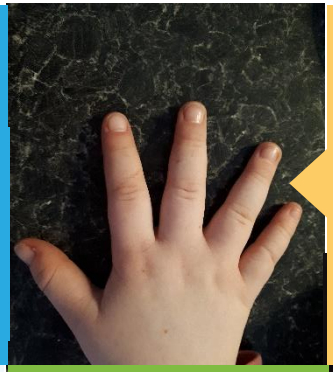
.

HP:0008551



Immunodeficiency

LOINC
94500-6
SARS

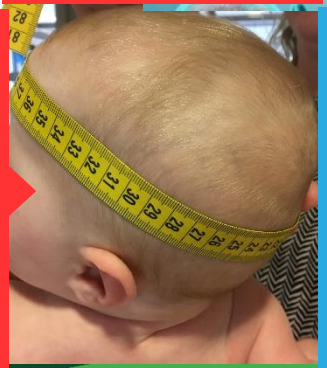


Coffin Lofry s
Tapered fingers

HP:0001182

Measuring Head Circumference

LOINC
8287-5



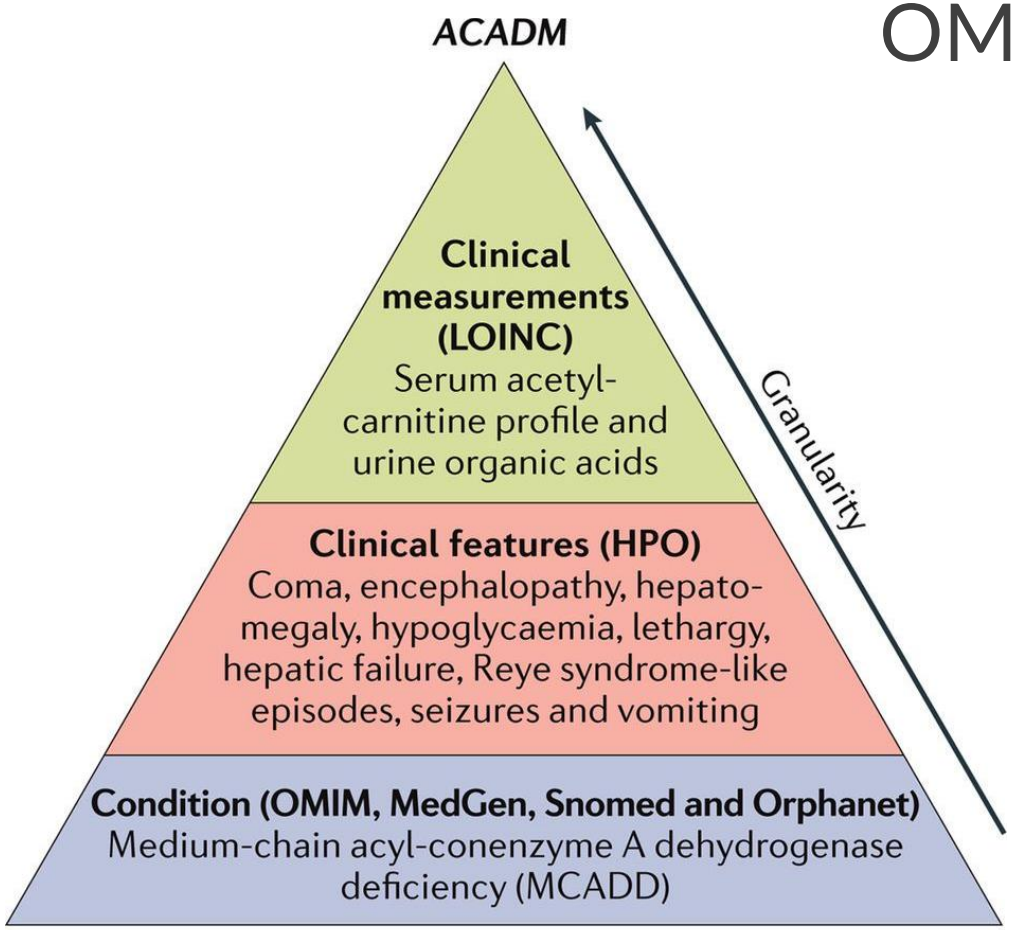
Neutropenia

LOINC
751-8
Neutrophils

Shwachman DS

ATC
A09AA02
Pancreatine
Vitamine A,D,E,K
Bo5XC

OMIM, HPO,LOINC



Medium-chain acyl-CoA dehydrogenase deficiency (MCAD deficiency or **MCADD**), is a disorder of fatty acid oxidation that impairs the body's ability to break down medium-chain fatty acids into acetyl-CoA.

50 YEARS OMIM
Human Genetics Knowledge for the World

Nature Reviews | Genetics

New variants found in Mendelian disease, what next? Review #bioinformatics scoring to prioritise 2017 https://www.nature.com/nrg/articles

twitter

Shwachman Diamond Syndrome

Symptoms

- Steatorrhea
- Failure to thrive
- Recurrent infections

Shwachman Diamond Syndrome- Management

- neutropenia
- pancreas insufficiency
- skeletal dysplasia
- developmental delay

Home / symptoom / Steatorroe

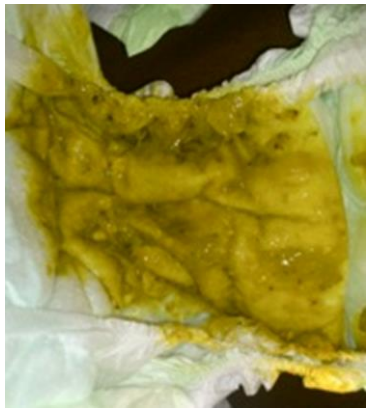
Steatorroe

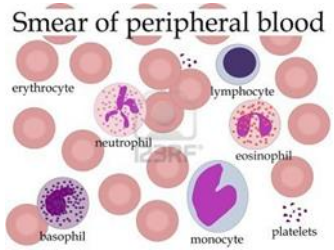
Steatorroe

of vetdiarree genoemd is waarbij de ontla
verteerd.

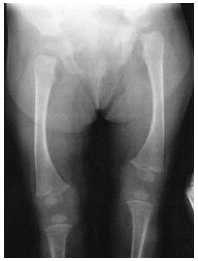
Een van de oorzaken, als bij Shwachmar
pancreas (alvleesklier) niet voldoende ve
voedingsstoffen als vetten, eiwitten en ko

Last modified: 5 januari 2019
LOINC
25907-7 Pancreatic Elastase in Stool
16142-2 : Fat [Mass/time] in 24 hour Stool
Functie





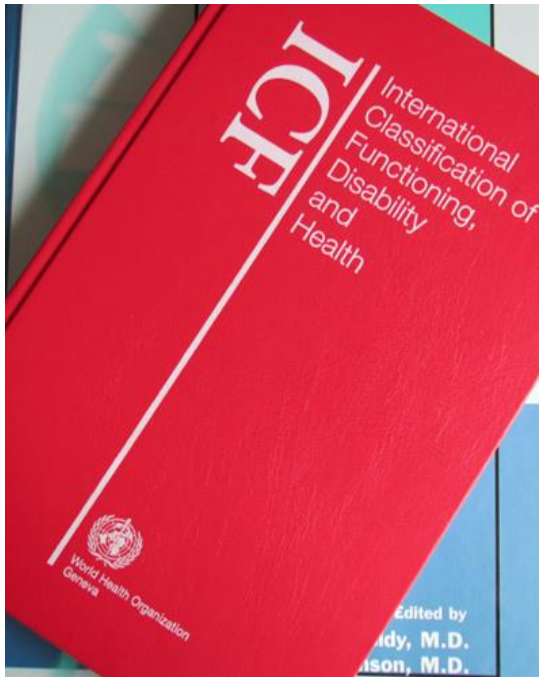
LOINC 751-8
Neutrophils in blood
Units:
number/volume ($10^3/\mu L$)



ICF : INTERNATIONL CLASSIFICATION of FUNCTIONING. DISABILITY and HEALTH

World Health Organization

Gowers's Sign

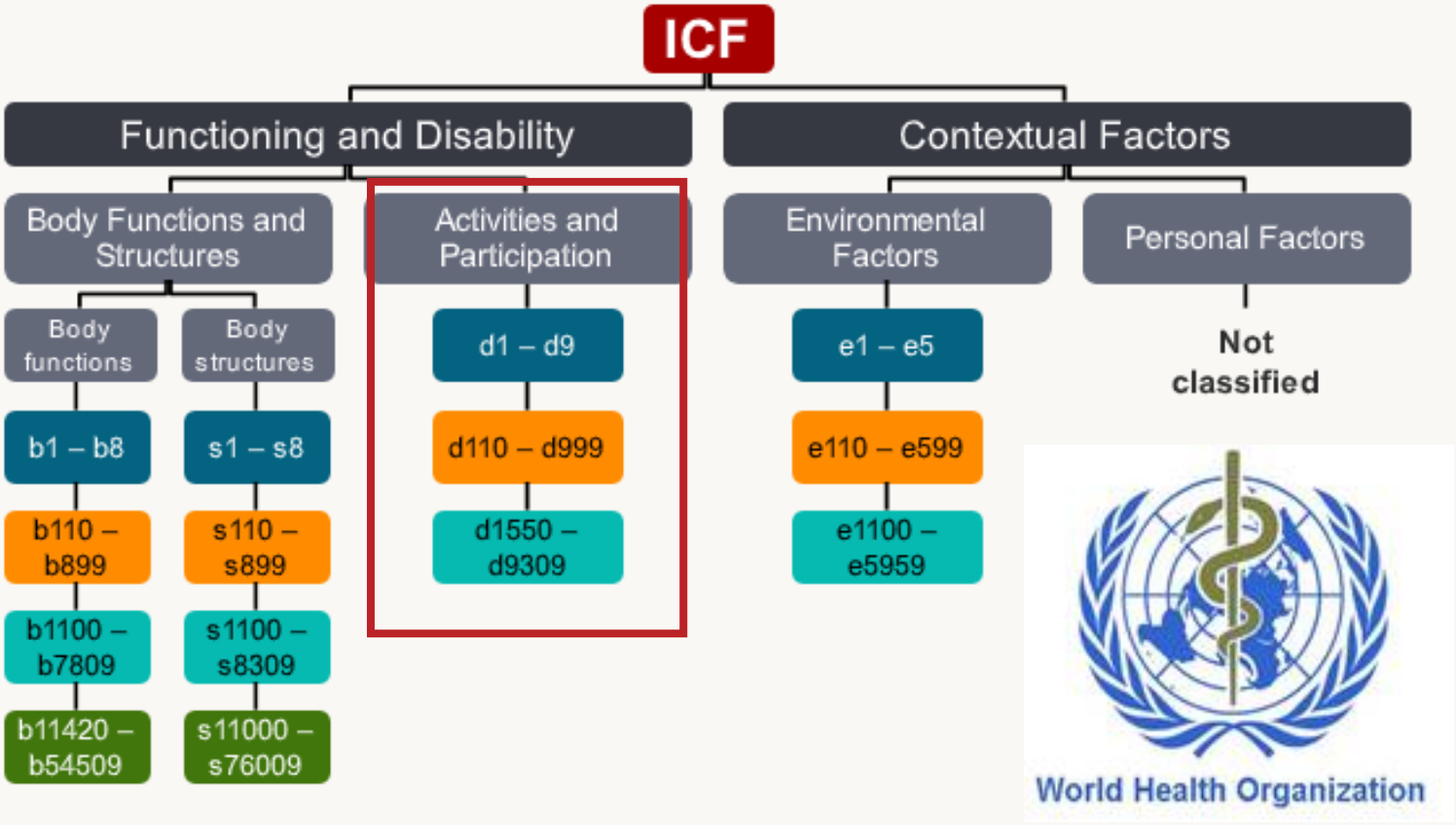


ICF-b 730 Muscular Power Functions

Boys with Duchenne Muscular Dystrophy Poland

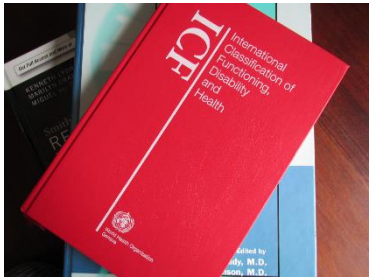
The structure and codes of the ICF

The ICF does this as well. In the ICF, ICF categories are like the geometrical objects in the previous illustration. ICF categories are placed in similar groupings of health and health-related domains and are organized in a hierarchical manner.



The following slides will explain how the ICF is structured and organized.

ICF in Rare Care World



rarecare.world

Anemia in thalassemia

Anemia as a symptom of Thalassemia major. Ch

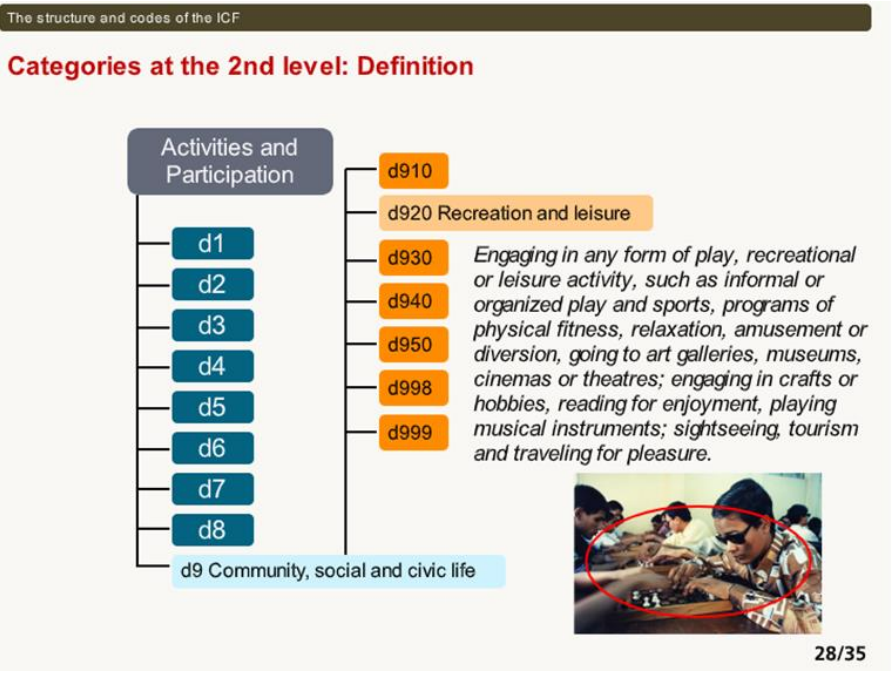
Social Support

- d 460 Moving around in different locations
- d 4750 Driving human-powered transportation
- d 570 Looking after one's health
- d 610 Acquiring a place to live
- d 640 Doing housework
- d 730 Relating with strangers
- d 770 Intimate relationships
- d 820 School education
- d 830 Higher education
- d 840 Apprenticeship (work preparation)
- d 850 Remunerative employment
- d 8501 Part-time employment
- d 870 Economic self-sufficiency
- d 9201 Sports

	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider							
d8501	**Part-time employment**	**0**	**1**	**2**	**3**	**4**	**8**	**9**
	With help or tool							
	Without help or tool							
	Explanation: Engaging in all aspects of work for payment on a part-time basis, as an employee, such as seeking employment and getting a job, doing the tasks required of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups. *Think of:* *does not deliver financial advantages next to security payment*							

ICF d 920.0

Recreation and leisure

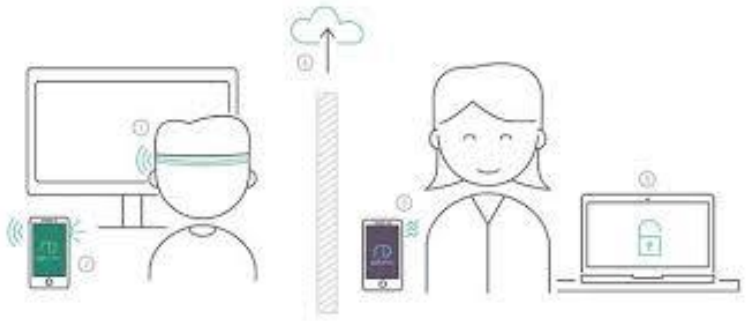


Indian Mother and Childcare
Kolkata, 2020

Epilepsy – assistive products- Health Technology Assessment

ICF d132
Acquiring Information

Mosaic ring chromosome 20



ICS › 11 › 11.180 › 11.180.01

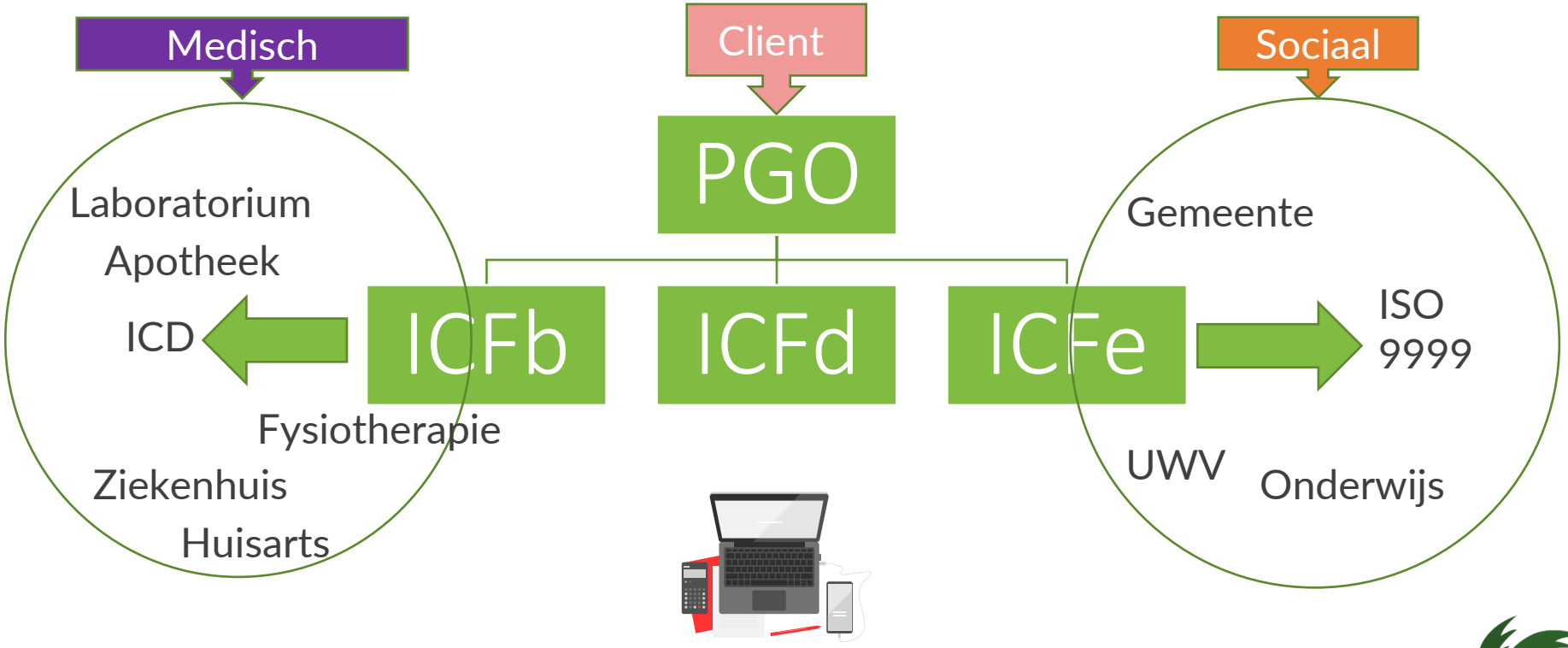
ISO 9999:2016

Assistive products for persons with disability — Classification and terminology

EPIHUNTER

Health Technology Assessment (HTA)

Client Centraal



REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

of 27 April 2016

on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)

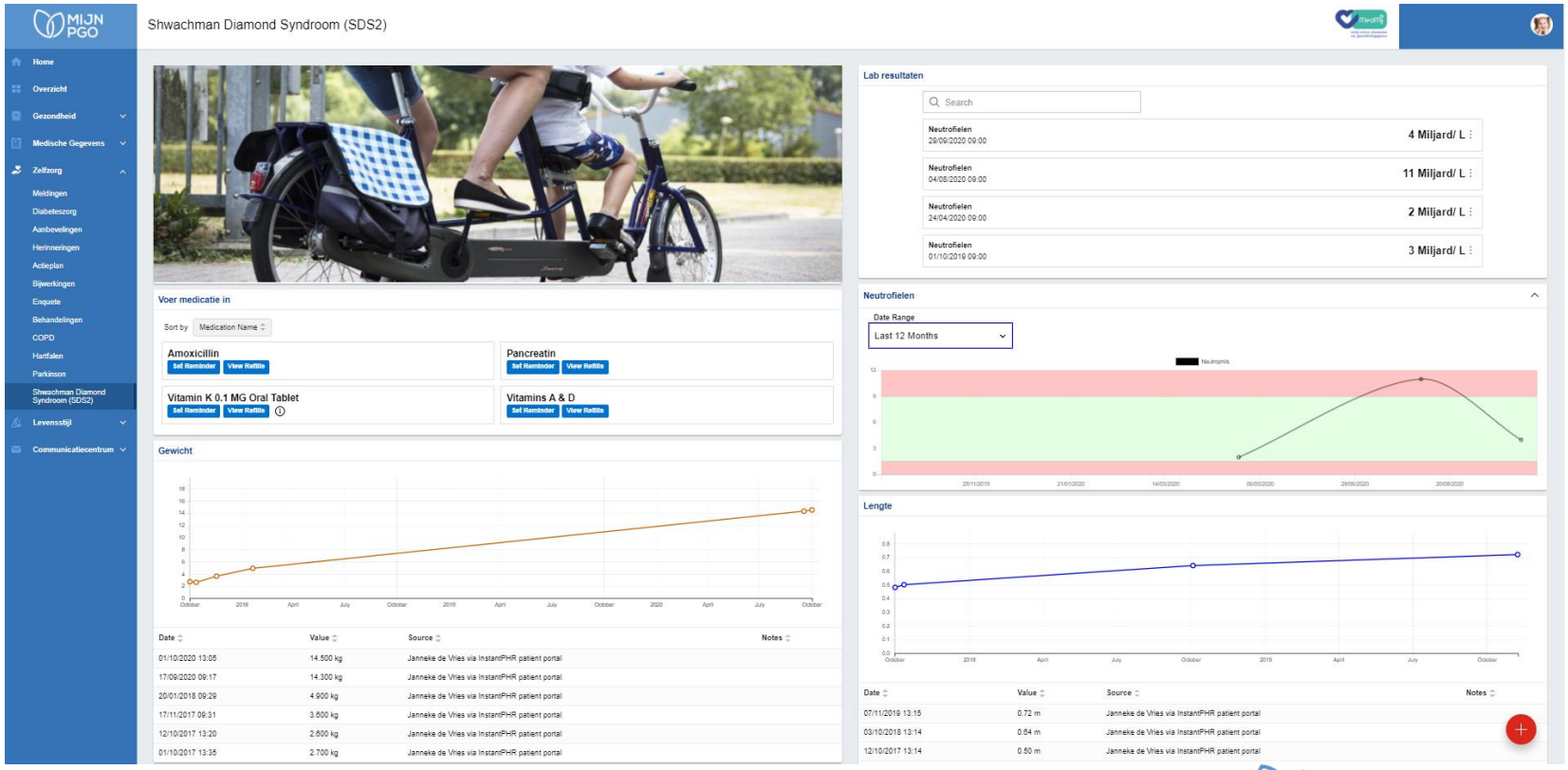
General Data Protection Regulation

Art. 20 GDPR

Right to data portability

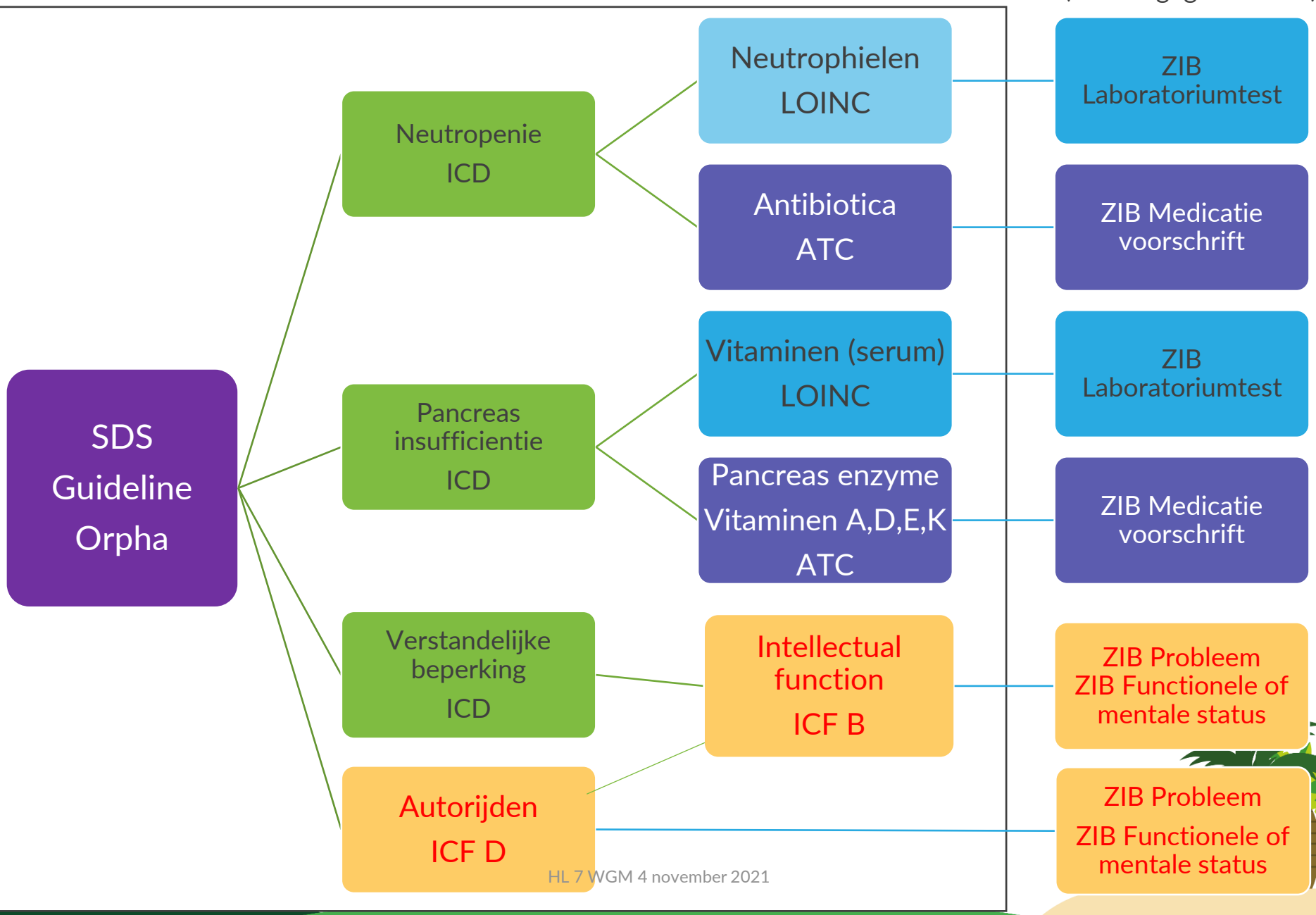
The data subject shall have the right to receive the personal data concerning him or her, which he or she has been provided to a controller, in a **structured, commonly used and machine-readable format** and have the right to transmit those data to another controller without hindrance from the controller to which personal data have been provide….

Eerste voorbeeldinrichting PGO (sept. 2020)



Rare Care World

MedMij ZIB's
(binnen gegevenssets)



FHIR Profile chronic condition

Home Artifacts

Table of Contents > **Home**

RarecareFHIRIG - Local Development build (v0.1.0). See the Directory of published versions

1 Home

This repository contains the FHIR resources for the "Een PGO voor iedereen" ("A personal healthcare environment for everyone") project.

Note: *All example content is example only!* It is based on Shwachman Diamond Syndrome (SDS) data from rarecare.world, but for brevity it is much shorter than the actual data would be.

- MedMij and the "PGO for everyone" project
- The RareCare Data Model
- The RareCare FHIR profiles
- The RareCare FHIR API

1.1 MedMij and the "PGO for everyone" project

The Netherlands has a national effort, MedMij, to provide all Dutch citizens with a personal healthcare environment, web or mobile. However, persons with rare diseases have trouble seeing their condition properly represented. Due to the rare nature of their condition, vendors are hesitant to invest in small populations. Having a machine-readable Rare Condition profile would enable vendors to simply read the necessary data to provide those persons with customized dashboards, graphs and questionnaires to address their conditions properly. Moreover, healthcare professionals, patient organizations and researchers could all benefit from the structured collection of data.

The "PGO for everyone" project aims to provide such a machine-readable API for PGO's. The definitions for specific rare conditions are published as FHIR resources. PGO's can pull those in with an API, and use the definitions to provide disease-specific dashboards and questionnaires for those rare conditions.

1.2 The RareCare Data Model

The Rare Care models are maintained at https://rarecare.world

and (only partially complete yet) https://decor.nictiz.nl/art-decor/decor-datasets-zaz-

From those resources FHIR profiles are generated. The basis is a Data Model of Rare Conditions:

REST API, compatible with FHIR/HL7 , one endpoint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        ]
    },
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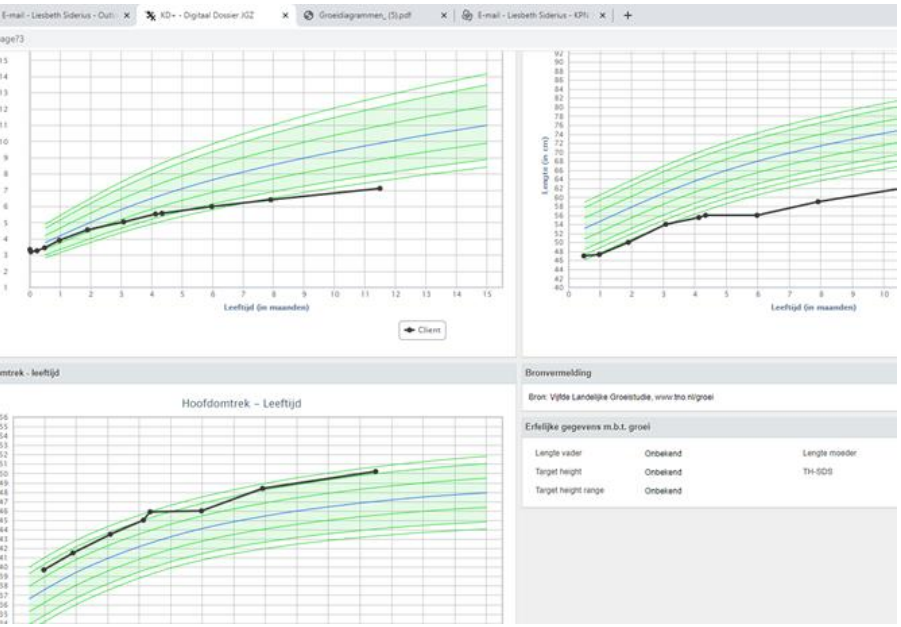
Achondroplasia ‘Dwerggroei)



Primary Care September 2021

- 2,5 year old boy diagnosis achondroplasia , sign of **autism**, association with the mutation FGFR3?
- 4 weeks old girl, normal weight, reduced length , large head, **FGFR3 DNA** analysis is performed

In nearly all instances achondroplasis is caused by a glycine to arginine substitution (G380R) in the FGFR3 protein:
OMIM #100800 Orpha:15

Pauli *Orphanet Journal of Rare Diseases* (2019) 14:1
https://doi.org/10.1186/s13023-018-0972-6

Orphanet Journal of Rare Diseases

REVIEW Open Access

Achondroplasia: a comprehensive clinical review

Richard M. Pauli

Achondroplasia

Pauli *Orphanet Journal of Rare Diseases* (2019) 14:1
https://doi.org/10.1186/s13023-018-0972-6

Orphanet Journal of Rare Diseases

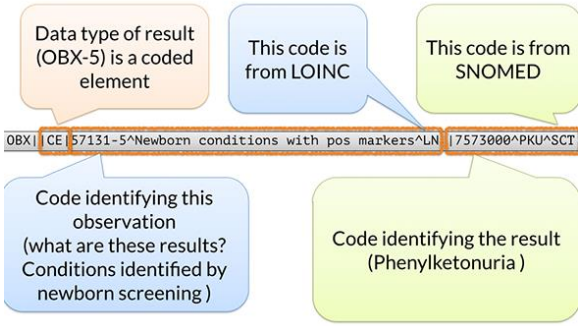
REVIEW Open Access

Achondroplasia: a comprehensive clinical review

Richard M. Pauli

Abstract

Achondroplasia is the most common of the skeletal dysplasias that result in marked short stature (dwarfism). Although its clinical and radiologic phenotype has been described for more than 50 years, there is still a great deal



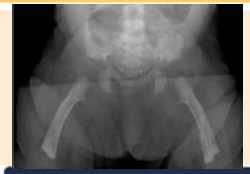
Remarkably few parents of average children understand the importance of routine measurement of growth – that growth is an excellent, nonspecific indication of general well-being. Plotting the growth of a child with achondroplasia on average stature charts will only confirm shortness and won't offer the same opportunity to use growth as a measure of health as it is used in average statured individuals. Therefore, standard growth charts specific for achondroplasia [61, 156] should be used (Fig. 15), and length or height measured at each encounter with the child's primary care provider. In addition to these hand-smoothed curves,

ICF International Classification, Functioning, Disability and Health

Achondroplasia

World Health Organization

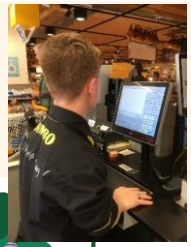
First Feature



Diagnosis
Achondroplasia

Medical Guideline

ICF : Body Functions & Structures



ICF: Activity Participation
D845 Acquiring, keeping and terminating a job

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

ICS › 11 › 11.180 › 11.180.01

ISO 9999:2016

Assistive products for persons with disability — Classification and terminology

Leave no one behind

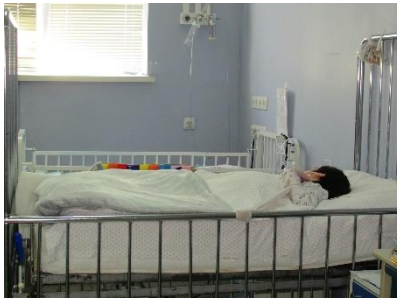
MedMij en Europese kinderartsen

The Netherlands

Day Centre
Coffin Lowrey Syndrome

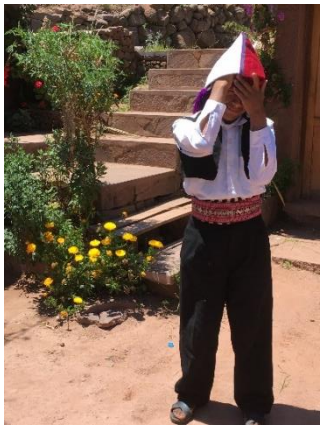
India

NIEPID
To be diagnosed



Georgia

Abandoned
Undiagnosed



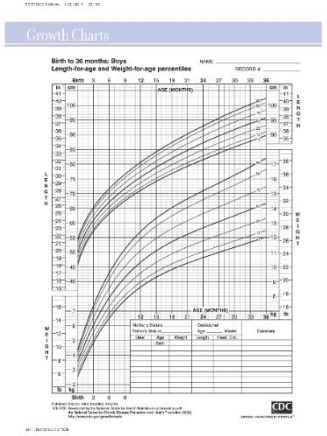
South America

Living with family
In rural village
‘ Birth trauma’

MedMij
veilig online uitwisselen van gezondheidsgegevens

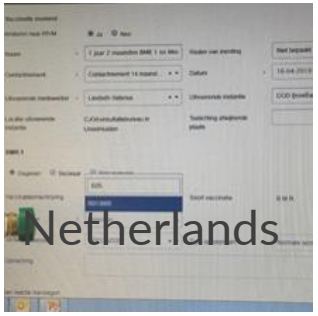
EAP Rare Diseases

World wide children are measured, examined, developmental screened, and vaccinated in Preventive child health

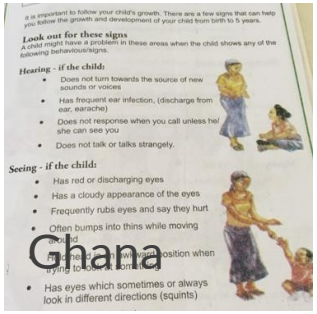


Growth
Development
Physical examination
Vaccination

Preventive Child Health Records

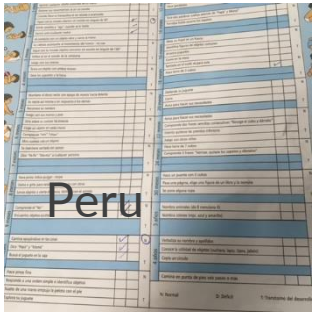


Netherlands



Ghana

Spain



Peru

Sri Lanka

Poland

cademy of Pediatrics
E HEALTH OF ALL CHILDREN

2015 Recommendations for Preventive Pediatric

Bright Futures/American Academy of Pediatric

mily is unique; therefore, these Recommendations for Preventive Pediatric Health Care are care of children who are receiving competent parenting, have no manifestations of any problems, and are growing and developing in satisfactory fashion. Additional visits may ry if circumstances suggest variations from normal.

These guidelines represent a consensus by the American Academy of Pediatri Bright Futures. The AAP continues to emphasize the great importance of conti comprehensive health supervision and the need to avoid fragmentation of care

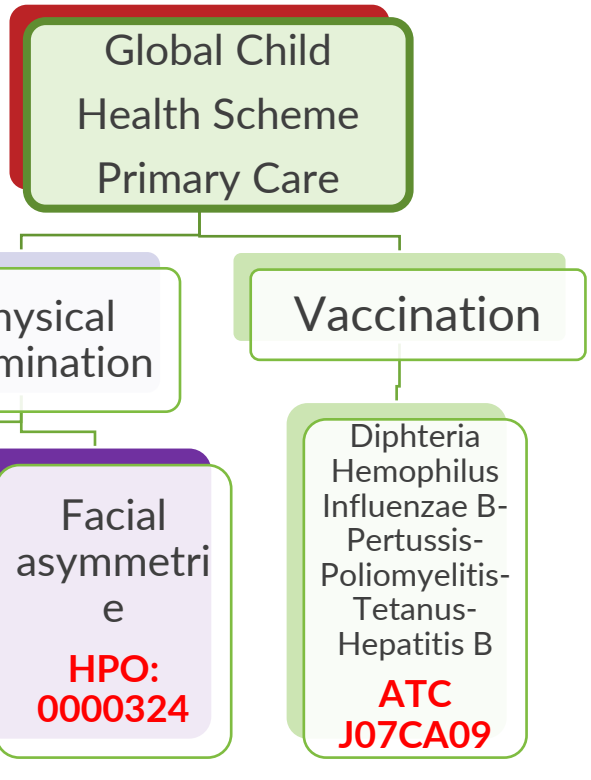
Refer to the specific guidance by age as listed in Bright Futures guidelines Shaw JS, Duncan PM, eds. *Bright Futures Guidelines for Health Supervision o and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatric

al, psychosocial, and chronic disease issues for children and adolescents may require ng and treatment visits separate from preventive care visits.

	INFANCY							EARLY CHILDHOOD									MID
AGE[1]	Prenatal[2]	Newborn[2]	3-5 d[2]	By 1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	30 mo	3 y	4 y	5 y	6 y	
HISTORY Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	
MEASUREMENTS																		
Length/Height and Weight		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	
Head Circumference		●	●	●	●	●	●	●	●	●	●	●						
Weight for Length		●	●	●	●	●	●	●	●	●	●							
Body Mass Index[3]												●	●	●	●	●	●	
Blood Pressure[4]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	
SENSORY SCREENING																		
Vision		★	★	★	★	★	★	★	★	★	★	★	★	●[7]	●	●	●	
Hearing		●[8]	★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	
TAL/BEHAVIORAL ASSESSMENT																		
Developmental Screening[9]								●			●		●					
Autism Screening[10]											●	●						
Developmental Surveillance		●	●	●	●	●	●		●	●		●		●	●	●	●	
Psychosocial/Behavioral Assessment		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	

International classifications as a tool for interoperability in child health

Towards a Global Integrated Digital Preventive Child Health Model



Oculo-Auriculo-Vertebral Spectrum/Goldenhar Syndrome
ORPHA:141132 Oculo-auriculo-vertebral spectrum
OMIM # 164210 HEMIFACIAL MICROSOMIA; HFM

One code = One meaning

ICPC: International Classification of Primary Care

HPO: Human Phenotype Ontology

LOINC Standard for identifying health measurements, observations, and documents

ICD: International Classification of Diseases

ATC: Anatomical Therapeutic Chemical Classification System

ORPHA: Classification of rare diseases

OMIM: Catalog of Human Genes and Genetic Disorders

Use of terminologies enables semantic interoperability between systems using HL7 CDA and FHIR

FHIR Profile Australian Child Digital Health

FHIR®© **Australian National Child Digital Health Implementation Guide**

Home | Guidance | Profiles | Extensions | Terminology | Search Parameters | Operations | Capability Statements | Downloads

National Child Digital Health Implementation Guide, published by National Children's Digital Health Collaborative (NCDHC). This is not an authorized publication; it is the continuous build for version v1). This version is based on the current content of https://github.com/hl7au/au-fhir-childhealth/ and changes regularly. See the Directory of published versions

Profiles Defined

These Profiles have been defined for this implementation guide.

Patient Profiles

- NCDHC Baby Patient - Demographic details of the Baby/Child Patient.
- NCDHC Expectant Mother Patient - Demographic details of the Expectant Mother Patient.

Consent Profiles

- NCDHC Consent Details - Consent profile to record access and use of patient record in NCDHC program.

AuditEvent Profiles

- NCDHC Audit Details - AuditEvent profile to record audit details of all actions performed in Data Hub.

OperationOutcome Profiles

- NCDHC OperationOutcome - OperationOutcome resource to represent error and informational scenarios in NCDHC.

Orders and Observation Profiles

- NCDHC Body Weight Vital Sign - Vital Sign profile to represent Weight of Body. This profile is used to record the Birth Weight as well.
- NCDHC Body Height Vital Sign - Vital Sign profile to represent Length of Body. This profile is used to record the Birth Height as well.
- NCDHC Body Mass Index (BMI) Vital Sign - Vital Sign profile to represent Body Mass Index (BMI).
- NCDHC Head Circumference Vital Sign - Vital Sign profile to represent Numeric value for head circumference

Universal Health Coverage, leave no child behind

Domestic general government health expenditure per capita, 2018 WOLD BANK

Country	Most Recent Year	Most Recent Value
Rwanda	2018	18.35
Netherlands	2018	3,444.81

https://data.worldbank.org/indicator/SH.XPD.GHED.PC.CD

The STIGMA

Laurien, from Rwanda, 4 october2021 on UHC

...females with **Type 1 Diabetes** either cannot be married or if they get married they are sometimes abused, or sometimes they choose to have children without being legally married and this is seen as a sin in Rwandan culture.

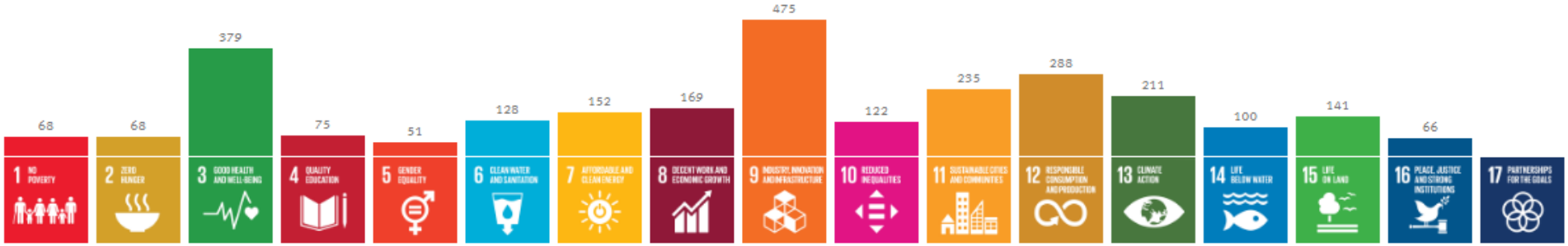
I know more than 200 who have died from T1D and mostly because of poverty.

ISO= International Standards globally recognized guidelines and frameworks

ISO | Standards | All about ISO | Taking part | Store | EN

IMPACT AT A GLANCE

ISO contributes to all of the SDGs. Here you can see the number of ISO standards that are directly applicable to each Goal.



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Martin Postma, IT Expert, Nederland
Mijn PGO, Nederland
InQdo, Nederland

Mensen met een zeldzame aandoening en hun familie

Mogelijk gemaakt door:

Siderius, L., Neubauer, D., Bhattacharya, A., Altorjai, P., Margvelashvili, L., Lamabadusuriya, S., Wierzba, J., Mazur, A., Albrecht, P., and Tasic, V. (2021). Universal Health Coverage “Leave No Child Behind”. Pediatria Polska - Polish Journal of Paediatrics, 96(1), pp.1-6. https://doi.org/10.5114/polp.2021.104822

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Stichting Shwachman syndroom Support Holland