

December 7th 2018
Brussels
Winter Meeting
European Academy
Paediatrics

Rare Diseases 11.30-12.15



1) Agenda

Welcome and approval of the agenda (*5 min*)

2) It can be done differently! (*20 min*)

3) Follow up on Spring meeting Sofia, Bulgaria 2018 (*5 min*)



4) UEMS MJC Rare and Undiagnosed Diseases (*5 min*)

5) Other business (*5 min*)



7 December 2018 Patient Solidarity Day

Safe Medication and Healthcare for All



- [Who We Are](#)
- [What We Do](#)
- [Get Involved](#)



Patient Solidarity Day

- [Global Patients Congress](#)
- [Patient Solidarity Day](#)
- 2018 theme

Patient Solidarity Day takes place each December. Thousands of people from around the world rally around one key issue facing patients and raise awareness by hosting events and showing support for the Day.

2) It can be done differently!

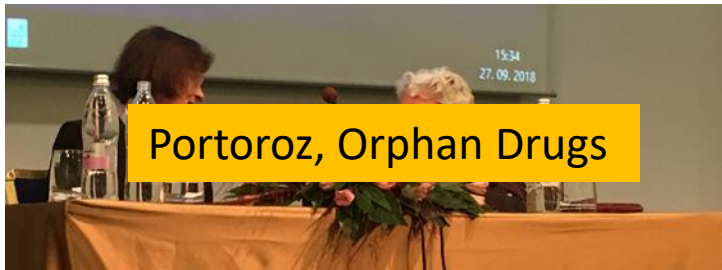
Patient organization takes a lead in Orphan
Drug development
Kees van der Graaf, past president Unilever
Europe

Discussion on orphan drugs



3) Follow up om Spring meeting Sofia, Bulgaria 2018

- Access to health document letter/article
- What's has been happening at national levels:



4) UEMS MJC Rare and Undiagnosed Diseases Report

activity = questionnaire 14/34 responders (summer 2018)

Q6 What should be included in a standardized core training on rare diseases?

Total responses	N=14	%
Awareness in general practice	13	93
Diagnostics	11	79
Treatments	9	64
Multidisciplinary approach	14	100
Patient involvement	12	86
Other	2	



**UEMS 60 years Brussels
19-20 October**

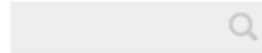
○ EAP Winter 2018

4)UEMS MJC Rare and Undiagnosed Diseases Report

**CME-CPD BRUSSELS
23-24 november**



UNION EUROPEENNE DES MEDECINS SPECIALISTES
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Areas of Expertise
CME - CPD
EACCME®
What is European accreditation?
Mutual recognition with the United States

Dear participants,

thank you for attending the Fourth UEMS Conference on CME-CPD

that took place in Brussels on 23-24 November 2018

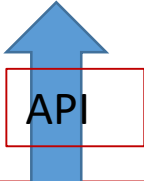
Please see below the presentations:

1. Start of the Conference programme

Harnessing meaningful
patient involvement
A path to effective health systems

5) Other business:

The screenshot shows a web browser window with the URL https://ec.europa.eu/info/law/better-regulation/initiatives/ares-2018-5986687/feedback/add_en?p_id=333036. The page header includes the European Commission logo and navigation tabs for 'Commission and its priorities' and 'Policies, information and services'. The main content area features a blue banner with the text 'Give your feedback on: Electronic health records – standard formats'. Below this, there is a section titled 'How to add your feedback' and a sidebar with various utility links like 'Vorige', 'Vooruit', 'Opnieuw', etc.



The screenshot shows the homepage of www.rarecare.world. The website has a green header with the text 'Building the Rare Disease knowledge and information ecosystem'. Below the header is a search bar with the URL 'www.rarecare.world' and a 'SEARCH' button. The main content area features the text 'Find and share knowledge about Rare diseases all over the world'. The footer includes the text 'EAP Winter 2018'.

EU- E-Health

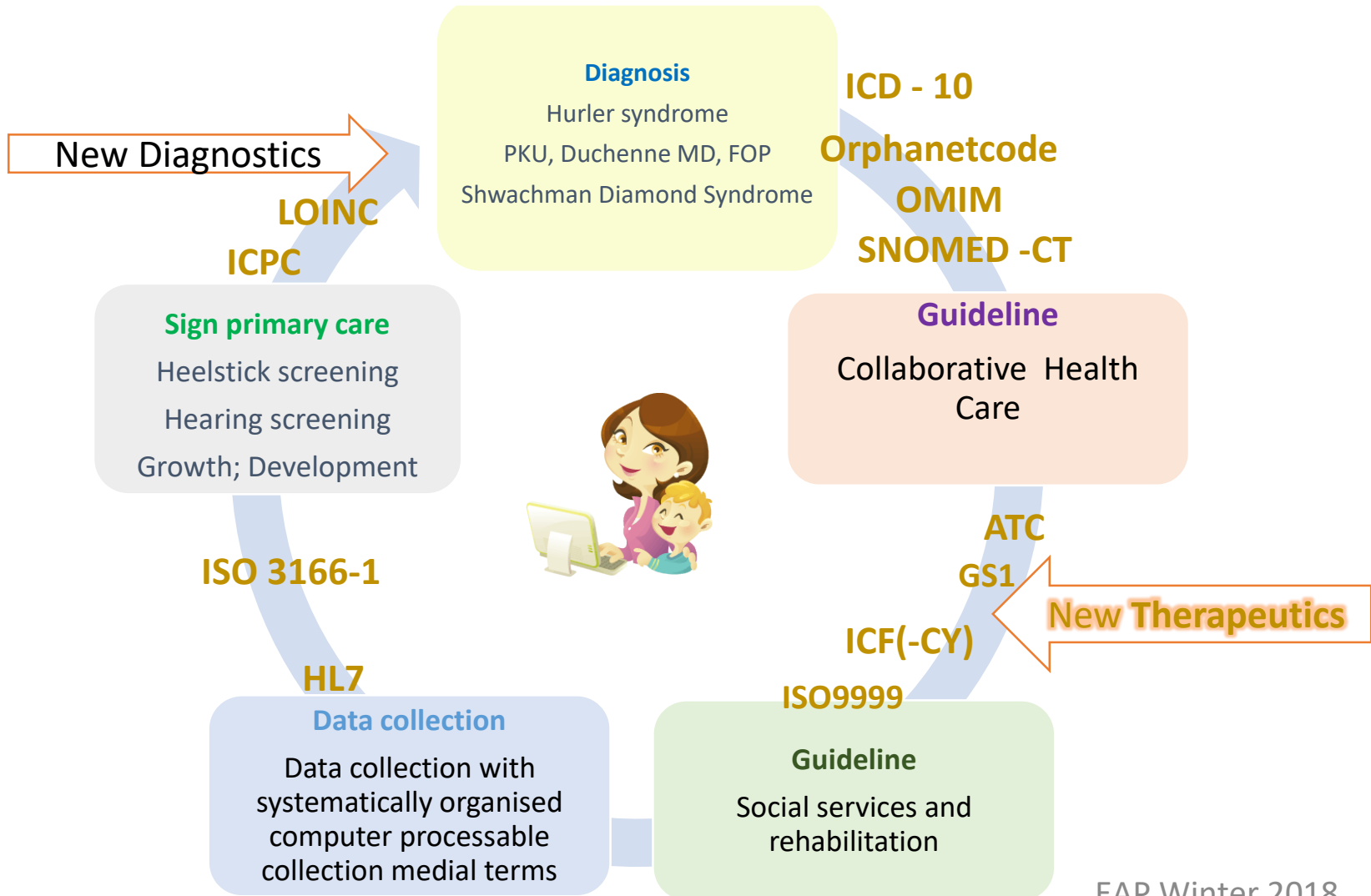
recommendations on how **electronic health records** can be accessed and shared more easily in every EU member country.

Make it easier for **patients, health professionals or other authorised parties** to use health data from different records across the EU – for example, to **avoid having to repeat medical tests** that have already been carried out in one country.

Give FEEDBACK until 20 December 2018



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)



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