

# Rare News from Norway 2017



helsenorge.no

National Helpline  
800 41 710



## E-LEARNING INNOVATION– SJELDEN.NO

Since 2015 Norwegian National Advisory Unit on Rare Disorders has been working on making e-learning courses for scholars, also applicable for patients and parents. At Rare Disease Day 2017 «[Sjelden.no](http://Sjelden.no)» was launched, and the number of pedagogical courses, illustrated and animated lessons are growing.

**Sjelden.no**

## NATIONAL PLANS AND STRATEGIES IN NORWAY

Norwegian National Advisory Unit on Rare Disorders have developed a five years strategy (2017-2021) for our services. Important aspects in this strategy is to inforce cooperation nationally and internationally, enhance our research capacity and quality and reassure user involvement i service development and research. The Norwegian Government have recently decided to establish a Norwegian National Plan for Rare Disorders, and NKSD plays an important role in planning and establishing this plan. The Norwegian Parliament was unanimously positive to such a plan in January 2017. *Photo: Stortinget.no*



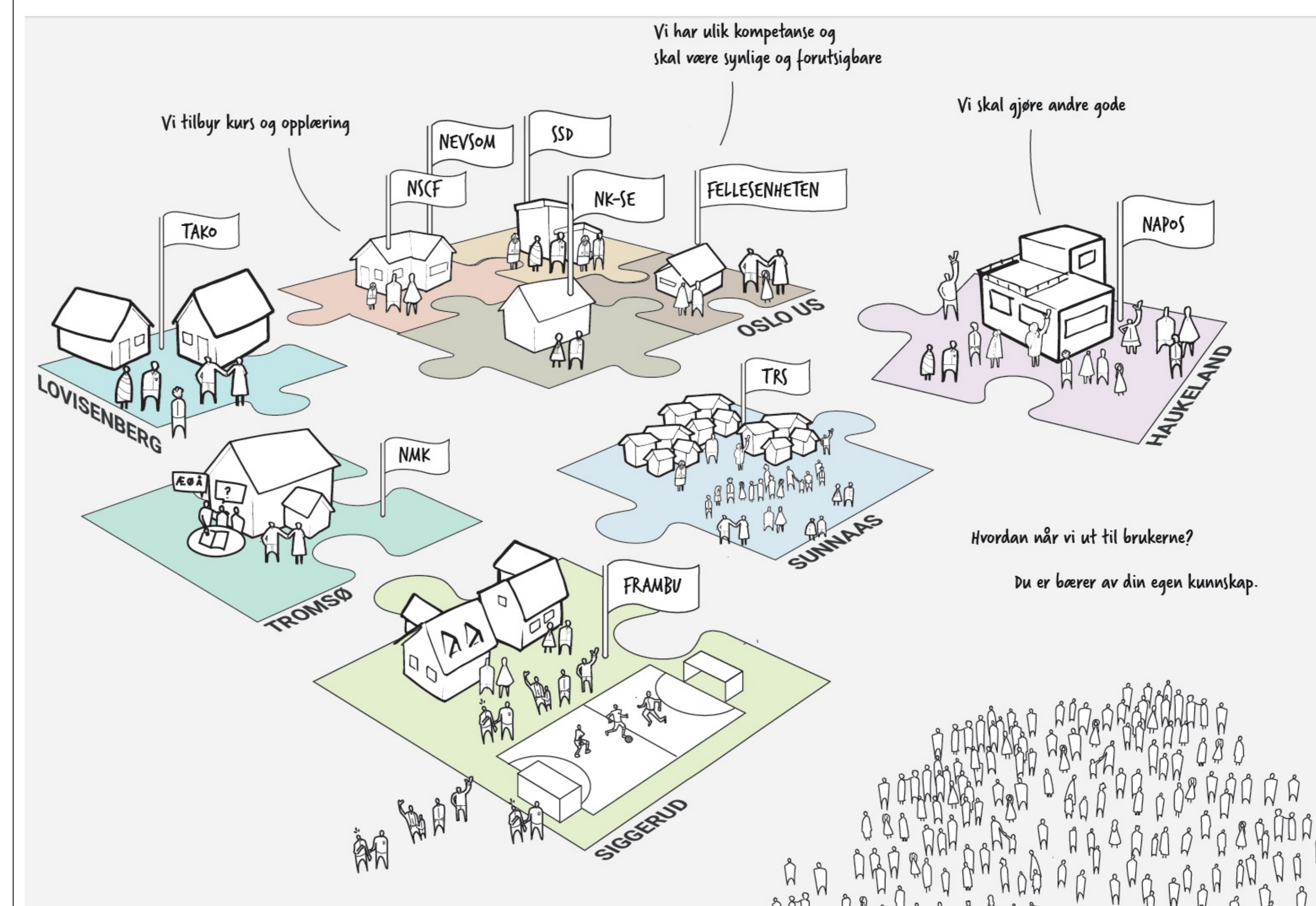
## A NEW NATIONAL REGISTRY ON RARE DISORDERS

Norway has initiated the work of establishing an Epidemiological Registry on Rare Disorders in Norway. Further information will follow in coming OrphaNetWork News.

## THE NATIONAL CENTRES FOR RARE DISORDERS IN NORWAY

The National Advisory Unit for Rare Disorders consist of nine national resource centers and a Central Unit. Each center is responsible for specific disorders. People with other rare disorders other than provided for by the centers can call the National Helpline for Rare Disorders.

## SERVICE DESIGN INNOVATION ON RARE DISORDERS IN NORWAY



Ill.: Halogen AS

During spring 2017 an innovation project on rare disorders was piloted in Norway with the help of a service design bureau. The aim was to map how patients, parents and scholars get in touch with the centres, and how they find their user experience. Follow ups are being considered during 2017-2018.

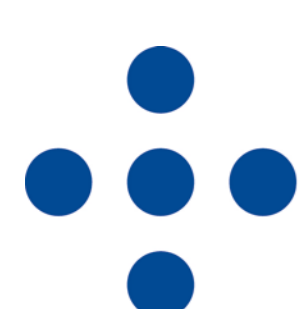
## VIDEO CONFERENCES AND LOCAL VISITING SERVICES

The use of video conference is increasing year by year. At the centres in Norwegian National Advisory Unit on Rare Disorders the numbers of reported video conferences to local service providers increased from 91 in 2015, to 217 in 2016.



Ill.: Bjugn kommune and Frambu.no

The 9 centres are: **Frambu** Resource Centre for Rare Disorders, The Norwegian **Porphyria Centre**, National Centre for **Rare Epilepsy-Related Disorders**, National **Neuromuscular Centre**, Norwegian Centre of Expertise for **Neurodevelopmental disorders and Hypersomnias**, Norwegian Resource Centre for **Cystic Fibrosis**, Center for **Rare Disorders**, **TAKO-centre** – National Resource Centre for Oral Health in Rare Diagnoses, and **TRS** National Resource Centre for Rare Disorders.



Norwegian National Advisory Unit on  
**RARE DISORDERS**