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<https://www.eurordis.org/>

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EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 894 rare disease patient organisations in

72 countries. We are the voice of 30 million people affected by rare diseases throughout Europe. **Radiorg (Rare Diseases Belgium) is part of EURORDIS.**

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<https://www.rarediseaseday.org/events/world>

<https://www.rarediseaseday.org/page/news/today-is-rare-disease-day-2020>

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## Rare Disease Day 2020 in Belgium

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Patient organisations in Belgium have participated in Rare Disease Day since its launch in 2008, organising activities every year. The past two years RaDiOrg, Rare Disease Belgium, has organised national campaigns. By uniting the efforts of all stakeholders around a joint, national campaign, RaDiOrg aims at showing that rare diseases are rare but many, that all affected and involved join forces in putting the rare diseases at the forefront of attention. We are united in the ambition to raise the attention of the general public and ask policy makers to address the specific needs of all concerned. **In January and February 2020 RaDiOrg and all members and partners are folding origami edelweiss to create a huge flower carpet in the heart of Brussels on February 29th. The edelweiss is our symbol of rarity. With this beautiful symbol we will show that we are rare but that we are many, that together we are strong.**

On Rare Disease Day (29<sup>th</sup> February 2020), the organisation gives 3 **Edelweiss Awards**: one in the category for 'patient or patient advocate', one in the category patient organization or project, and **one in the category for a professional in health care.**

List of nominees in each category: <https://www.radiorg.be/nl/de-genomineerden-voor-de-edelweiss-awards-2020/>

On the facebook page of Radiorg.be, and facebook page of 'centrum voor menselijke erfelijkheid' you will find more information and photos, and the website of our hospital ☺.

Press release from our hospital (02.03.2020):

### **Edelweiss Award for Professor Ann Swillen**

Professor Ann Swillen, clinical educational psychologist in the Centre of Human Genetics in UZ Leuven, received the Edelweiss Award in the category 'healthcare professional' last Saturday. The Edelweiss Awards are presented annually by RaDiOrg, the Belgian umbrella association for people with rare diseases, to individuals and organizations that provide special merit for rare diseases in Belgium.

### **Commitment to patients with 22q11 DS**

The jury's choice fell on Professor Swillen because of her "incredible commitment to the care of patients with rare diseases and, in particular, patients with 22q11 deletion syndrome (22q11 DS)". She is the initiator of numerous research projects on 22q11 DS and leads national and international research projects. In addition, the jury appreciates her open and clear communication with patients and parents. A concrete example of this is the information and activity package 'Together we lay the puzzle' that she recently developed. Professor Swillen also organizes Dale & Do Sessions for teenagers with a 22q11 DS to talk about their thoughts and feelings and increase their self-confidence.

5 nominations for UZ Leuven:

In addition to Professor Swillen, four other UZ Leuven employees were nominated in the category 'healthcare professional'. Prof. Dr. Liesbeth De Waele (pediatric neurologist), Prof. Dr. Wim Wuyts (pneumologist), Marc Doods (production manager at the clinical pharmacology centre) and Sam Geuens (psychologist of the Epidermolysis bullosa-team) were also recognised for their optimal care for people with a rare disease. In addition to 'healthcare professional', Edelweiss Awards were also presented in the categories 'extraordinary patient' and 'patient association'.



Centrum Menselijke Erfelijkheid - Center for Human Genetics

@CentrumMenselijkeErfelijkheid

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### Berichten



Centrum Menselijke Erfelijkheid - Center for Human Genetics

1 maart om 12:03

Radiorg.be zet elk jaar een persoon of organisatie in de bloemetjes vanwege een bijzondere verdienste voor zeldzame ziekten in België. Dat doen ze met een Edelweiss Award, genoemd naar de zeldzame bloem die ook het symbool van de organisatie is. De prijs werd gisteren uitgereikt in Brussel, ter gelegenheid van internationale #RareDiseaseDay.

Dikke proficiat aan prof. Ann Swillen, zij kaapte gisteren de award weg voor 'Professional in de gezondheidszorg'! 🎉  
Ann ontwikkelde dit jaar 'Samen leggen we de puzzel', een info- en doepakket voor kinderen en hun ouders dat de zeldzame genetische aandoening in het gezin bespreekbaar moet maken.  
Meer info vind je hier: [www.samen-leggen-we-de-puzzel.be](http://www.samen-leggen-we-de-puzzel.be)



Radiorg.be 😊 trots in Hôtel de ville de Bruxelles.  
1 maart om 05:32

🇫🇷 Fière de vous annoncer les lauréats des prix Edelweiss 2020!  
🇳🇱 Trots u de laureaten van de Edelweiss Awards voor te stellen!

Dans la catégorie/In de categori...  
Meer weergeven

Marthe Van Damme en 30 anderen

3 opmerkingen