

### PERSONAL INFORMATION **Cathalijne van Doorne**

#### WORK EXPERIENCE

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- November 1991-June 1998 **Associate Publishing Editor**  
Elsevier Science (Netherlands)  
Guide medical scientific books through the production process.
- December 1989-July 1991 **Associate Publishing Editor**  
Oxford University Press (United States)  
Guide medical scientific books through the production process.
- 1998- 1999 **Management Assistant**  
Ineas Insurance Company (Netherlands)
- 1999- 2001 **Internal Affairs**  
ADVORAAD (Netherlands)  
Organise internal affairs of a law-office.
- 2004- 2006 **Projectmanager**  
UWV (Netherlands)  
Organize a reorganisation.

#### EDUCATION AND TRAINING

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- September 1980-October 1989 **University degree in Medical Biology**  
University of Amsterdam (Netherlands)  
Medical Biology - research on relation between protein content of food and malaria falciparum in rats.

#### ADDITIONAL INFORMATION

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- Expertise** I am a Patient Representative.  
Since my diagnosis of Ataxia (SCA6), a neurological disorder, I decided to change my life. I stopped working and I became involved as a patient representative.  
In my work as a patient representative my background in medical biology is very helpful.  
2014 - present: Vice President of the European Federation of Neurological Associations.  
I am involved in the "scientific" part of the EFNA representation:  
Chair of the EAASM/ASOP eu: european alliance for acces to safe medicines and european acces to safe online pharmacies.  
Try to involve more patient organizations in the good work of the EAASM.  
Try to inform as much patients as possible of the dangers of buying medicines online. - Ended November 2018.  
Chair of EuropaBio Patients Bio-Forum  
To discuss with all stakeholders topics of interest like: biologics vs biosimilars, off-label medicines, health technology assessment etc. - Ended May 2017.  
Advisor to Biopontis. Advise Biopontis how to involve patients in clinical research, how to reach patients. Help BioPontis in writing for patients (questionnaires, informed consent (future), information

leaflet (future). - Ended 2017.

Organise (with others) a workshop in the Netherlands on pharmaceutical pricing and reimbursement. (5 november 2016).

Board Member of Euro-ataxia (2004 - 20218) President of Euro-Ataxia (May 2018)  
As President I represent euro-Ataxia at meetings of Eurordis and the EFNA.

President of the Dutch Brain Council (platform of dutch neurology patient organizations).

As a board member we decide on common topics to discuss and to be presented at the meetings with our member organisations (4x/year). A very succesful concept. Ended August 2018.

Member of the BBMRI advisory board. (2016 - 2018)

Member of the patient board of COSYN (2016 - ) COSYN aims to address the basis of intellectual disabilities (ID), autism, and schizophrenia by studying the genes and pathways involved in this process and by identifying the interactions through which disease develops in normal and in disease conditions, with an emphasis on synaptic function, as early steps of neuropsychiatric disorders are expected to impact synapse function.

Patient representative in PREPARE (2016 -2019) A research project in which experts from all over the world are involved. Preparing for therapies in autosomal recessive ataxias.

Patient representative/Board Member in the ERN-RND.

Steering committee ERN (2018 - 2019 )

Member of the Patient Panel of the NPF (the Netherlands) - reviewing research proposals on patient participation.

Member of the Scientific Evaluation Panel of ZonMw (the Netherlands) (2018 - present) Program: Good Use Medicine

Member of the Scientific Evaluation Panel of ZonMw/KCE (NL/Be) (2018 - )

Graduated from Eurordis Summerschool (2017)

Graduated from Eurordis Winterschool (2018)

March 2019 - Patient member of the PRAC.

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