



EURORDIS Digital School

on Social & Digital Media

Ågrenska Resource Centre for Rare Diseases
8-9 October 2019

*A capacity-building programme for patient advocates
on social and digital media*



Co-organised by ÅGRENSKA



The EURORDIS Digital School is provided
via the EURORDIS Open Academy.

EURORDIS.ORG

Organisers:

The **EURORDIS Digital School** is organised by:

EURORDIS-Rare Diseases Europe

Plateforme Maladies Rares

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The training is carried out by **3MONKEYS**|ZENO
[3 Monkeys Zeno](#)

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Venue:

[Ågrenska Resource Centre for Rare Diseases](#)

Lillövägen, Lilla Amundön

43658 Hovås, Sweden

Introduction

The [EURORDIS Digital School on Social & Digital Media](#) consists of two days of face-to-face training. A series of online training modules will also be available from 2020.

The first edition of the face-to-face training of the EURORDIS Digital School will take place on 8-9 October, at the [Ågrenska Resource Centre for Rare Diseases](#), in Gothenburg.

The EURORDIS Digital School aims at empowering patient advocates, working with rare diseases and rare cancers, to use **digital communication tools** to improve the strategic outreach and community-building capacities of their organisations.

The training topics covered include understanding social and digital landscapes, creating and nurturing empowered communities, building effective channels and reaching the right people.

25 patient advocates, working with rare diseases and rare cancers, from around Europe, will take part in the first face-to-face training of the EURORDIS Digital School. The application process is now closed: **78 applications from 31 countries** have been submitted. The results will be announced to all the applicants by mid-July.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. EURORDIS works across borders and diseases to improve the lives of people living with a rare disease. EURORDIS' vision is to enable better lives and cures for people living with a rare disease.

Ågrenska Resource Centre for Rare Diseases

Ågrenska is a national Resource Centre for Rare Diseases, providing programs for children and adults with disabilities, their families and for professionals supporting the family. Striving to be a progressive and creative meeting place between needs and knowledge, Ågrenska aims to contribute to people's coping with everyday life and empower them to become as independent as possible.

3Monkeys Zeno

3Monkeys Zeno are a global creative communications consultancy. 3Monkeys Zeno deliver insight-led creative programmes covering a broad range of communications including physician, patient and media relations, influencer marketing, scientific messaging and thought leadership. They blend teams of Healthcare specialists with experts in Creative & Analytics, Consumer Brand Marketing, Corporate Reputation, Technology, Digital and Social to help clients navigate and lead the global shifts towards preventative healthcare, personalised medicine and digital health.

Tuesday October 8, 2019

Time	Session, Session detail and Trainer(s)
12:30 – 14:00	Registration & Lunch
14:00 – 15:00	Welcome & Introduction Workshop overview, objectives, programme structure, housekeeping <i>Raquel Castro, Open Academy Director, Social Policy Director, EURORDIS</i> <i>Robert Hejdenberg, Chief Executive Officer, Ågrenska Foundation</i> <i>3 Monkeys Zeno</i>
15:00 – 16:00	PO Scene Setter Understanding the social and digital landscape in a patient organisation context <i>Denis Costello, Executive Director, CML Advocates Network</i> <i>Lucy Michaeloudis, Junior Communications Manager, EURORDIS</i> <i>Ciaràn Scott, Communications Manager, AKU Society</i>
16:00 – 16:30	Coffee break
16:30 – 17:30	Plan & Create for Social Success Building effective channel, campaign and content strategies <i>3 Monkeys Zeno</i>
17:30 – 18:30	The Power of Community Creating and nurturing empowered communities <i>Richard Millington, Founder, Feverbee, tbc</i>
18:30 – 19:30	Visit to Ågrenska <i>Ågrenska's team</i>
19:30 – 21:00	Welcome Dinner at Ågrenska

Wednesday October 9, 2019

Time	Session and Trainer(s)
08:30 – 09:30	Where Now, Where To? Audits, measurement and goal-setting for social media <i>3 Monkeys Zeno</i>
09:30 – 10:30	Reach for the Skies Reaching (more of) the right people – content optimisation, reactive content and working with influencers <i>3 Monkeys Zeno</i>
10:30 – 11:00	Coffee Break – Handout of Certificates & Group photo
11:00 – 12:00	Developing Your SEO Strategy Practical session – the SEO Triangle and tools for keyword and link-building strategies <i>Tom Lillywhite, Founder, Wilder Digital</i>
12:00 – 13:00	Creating Great Video Practical session – options for cost-effective video production, tips for producing great content, and free editing and effects tools <i>3MonkeysZeno</i>
13:00 – 14:00	Lunch
14:00 – 15:00	Looking to the Future The patient / HCP relationship in the context of digital evolution <i>Dr. Alberto Tozzi, Chief Innovation Officer, Bambino Gesù Children’s Hospital</i>
15:00 – 15:30	Closing session Learnings, next steps, feedback <i>Raquel Castro, Open Academy Director, Social Policy Director, EURORDIS</i> <i>3 Monkeys Zeno</i>
15:30	Departure