

SOCIAL MEDIA TRAINING

BY PATIENT ORGANISATIONS FOR PATIENT ORGANISATIONS!

Applying the learning from the EURORDIS Digital School & customising it to Swedish context

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Background

The idea to launch this training was born when three representatives of Swedish Patient Organisations and members of Rare Diseases Sweden participated in EURORDIS Digital School on Social & Digital media, hosted by Ågrenska in Göteborg, October 2019. An online Swedish language programme was developed by these three members, and is based on the most important lessons of the EURORDIS Digital School programme - summarized, translated and adapted to the Swedish context. Roll out of the online training has begun and is staged in modular form. The specific content of this programme is of the entire responsibility of Rare Diseases Sweden. The training is targeted at those working for a patient organisation in Sweden who are responsible for spreading information and increasing awareness on social media of a rare disease.

Purpose

- To give out the basics in getting active on social and digital media so patient organisations new to this are effective from the get-go.
- To help those patient organisations who are already active to take their social media to the next level.
- To build the overall social media competencies of patient organisations in Sweden so that rare diseases in the country get a higher visibility.



Design

The online training is a mix of theory and practice in eight parts. Case studies from Swedish patient organisations are included in order to show the participants how the techniques have been successfully applied.

Conclusions

Through increased strategic activity in social media by patient organisations, our voice will be stronger and our impact greater as we strive to ensure that rare diseases are recognized as a national health priority in Sweden and rare disease patients have better access to adequate medical and social care.

For more information on the programme, visit
www.sallsyntadiagnoser.se

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