Nordic hypoPARA Organisation.

Activity plan 2016 to 2018.

The following plan has been proposed by the Board and approved by the General Assembly as activity plan for the Nordic hypoPARA Organisation, at our General Assembly in May 2016.

**Contact with and between members:**
Telephone contact is for Nordic hypoPARA extremely important in order to keep close connection to our members. A special focus on connecting new members and secure they feel close as from the beginning is evident. Continued support to old members.

**Advice and information to our members:**
We will continue providing advice and guidance by telephone.

The Facebook group is now used primarily just to get information from the association. The Board and General Assembly have in this context concluded that it is important that we take good care of the association's good reputation, something which benefits each member.

**Information from the Organisation to the members:**
Mails will be sendt regularly, MailChimp and/or use the Facebook page of the organisation.
Operating subsidies from Bufdir (the Directorate for Children, Youth and Family Affairs):
We are in close contact with Bufdir in order to continue applying for operating subsidies from Bufdir annually through Altinn.

New brochures:
We have received permission from the ESE (European Endocrinology Association) to translate their patient brochure, which was made in connection with the new European guidelines in the treatment of our disease. The permission given us applies to the Nordic languages. The topics of the brochure are: "Treatment of chronic hypoparathyroidism in adults.” The Norwegian brochure has already been approved by ESE. Correction of the translation was made by Professor Bollerslev, as he was the chairman of the expert group at ESE. We will continue with the other Nordic languages. They will also be printed out and sent as many Hospital sections in endocrinology as possible. We have used our own graphic designer to help us with the brochure in Norwegian.

Emergency cards:
Cooperate with Roas/ National Societies in Endocrinology in our need for Emergency cards:
The cards should be intended to support the patient's contact with doctors and other health workers in cases where they become injured or ill. The text on the card should inform the doctor about emergency treatment to be administered and prevent errors and delays in emergency treatment.

In addition we need Emergency medical ID on necklaces and bracelets.

National Guidelines on the treatment of Hypopara in acute situations:
Make contact to Dr. Kiarash Tazmini in Norway. He is a specialist and researcher on electrolytes. We need guidelines to inform doctors about emergency treatment.
Website:
We edit and enhance our new website, with the help of external resources.

Shire:
Explore opportunities in the good contacts and cooperation with the medical company, Shire. This company will contribute a lot in the coming years for improved treatment, research and knowledge of our illness.

The ROAS registry (The registry for organ-specific autoimmune diseases):
Continue the good cooperation with the ROAS registry. The study on Epidemiology and health related quality of life in hypoparathyroidism in Norway, was published in May 2016, which we were involved.

Cooperation with experts on our disease; nationally and internationally.

World Awareness Day June 1 st. Verdensdagen 1. juni:
We continue to use our own Nordic Awareness Logo. Seminars for patients and/or endocrinologists.

Contact to the National Advisory Unit on Learning and Mastery on health:
Closely follow up our cooperation with the National Advisory Unit on Learning and Mastery on health at OUS (Oslo University Hospital)

Theme evenings and seminars:
To strengthen unity and knowledge, we are working to arrange more seminars.

Our Medical Consultant:
Continue the good cooperation with Professor Fink Eriksen. As a nursing consultant, our President will continue to support Professor Erik Fink Eriksen by educating members with the technical devices on the continuous administration of PTH via insulin pumps.
Medical expert group for Norway:
Suggestions:
South-East Norway: Professor Erik Fink Eriksen
North Norway: Professor Ragnar Martin Joakimsen
West Norway: Professor Eystein Husebye/ Dr. Marianne Astor
Middle of Norway: Head of Endocrinology at the University hospital in Trondheim; Kristian Fougner.

Blood-calcium home testing:
Focus is to find a company that shows interest in developing a home tester for free ionized blood Calcium measurement.

Dental health:
Work on documenting research studies towards Helfo (Health Economics Administration). Hoping for new research studies on our disease related to dental health.

Thyroid surgery:
Continue to support our members to apply for compensation.

Swedish Organisation:
Found a National organisation for Sweden; in the same way we helped Denmark in 2012. Become their Umbrella Organisation. We hope for support in translating by-laws from Norwegian to Swedish. Founded to meet the criterias for Eurordis membership.

Cooperation with the Swedish National Board of Health and Welfare
Cooperation on Hypoparathyroidism in their Swedish Knowledge database on Rare Diseases.

Cooperate with Rare Diseases Sweden and Eurordis
Finland:

Cooperate with Professor Kai Krohn.
Helsinki University Hospital Research Institute

State Authorised Public Accountant and external accountant:
Continue cooperation with our State Authorised Public Accountant: Stiansen & Co AS and External Accountant: Sipak regnskap og økonomi AS.