Financial support for Eir Nordic is provided by Jazz Pharmaceuticals.

Eir Nordic

Eir Nordic Day

Eir Nordic day Posters and workshop outcome

Eir Nordic Meeting
17th October 2025
Sollentuna, Stockholm

M-DK-EPL-2500010
M-SE-EPL-2500025
M-FI-EPL-2500002

EPILEPSI FORENINGEN
Epilepsiforbundet Dravet syndrom
Svenska Epilepsiförbundet
epilepsialiitto
Epilepsiforbundet
Jazz Pharmaceuticals

Introduction

On 17 October 2025, 50 care professionals working with people living with epilepsy and intellectual disability came together to share experiences, exchange perspectives, and discuss best practices in care.

The meeting was organised by the Nordic epilepsy organisations, with financial support from Jazz Pharmaceuticals, and aimed to recognise the individuals and organisations who go above and beyond in supporting this community.

The programme included educational presentations, best practice poster sessions, and a collaborative workshop focused on identifying opportunities for future care innovation.

This document compiles the posters and key outcomes from the workshop discussions.

01

Best practice sharing posters

Eir Nordic

The Treasure Room

BEST PRACTICE SHARING

COUNTRY
Sweden

ACTIVITY OWNER
Annie Egelin

BACKGROUND

- Healthcare visits can sometimes be perceived as something negative for children and adolescents, particularly when they involve procedures such as blood sampling or injections.
- The Treasure Room was created so these children and adolescents can leave the visits on a more positive note.
- The Treasure Room is intended for children and adolescents visiting the neurology outpatient clinic. They may enter after completing a procedure (e.g., blood sampling, injection) or following a healthcare visit that was perceived as challenging.
- Inside the Treasure Room, each child or adolescent is invited to select a gift of their choice.
- The aim is to help the child or adolescent associate the healthcare visits with a more positive experience by concluding it with something enjoyable.

APPROACH

- Two years ago, I was given permission to clear out one of the clinic's storage rooms and fill it with gifts.
- The gifts are mainly purchased with money allocated to our clinic by the Astrid Lindgren Foundation, from which I regularly apply for financial support to restock the room with gifts.

OUTCOMES

- Often children and adolescents look forward to upcoming visits/ procedures because they know they get to go into the Treasure Room afterward.
- Many guardians are pleased that we have gifts suitable for everyone regardless of age and diagnosis.
- The room also brings joy to healthcare staff as they get to conclude the visit on a high note for the patients.

NEXT STEPS & REFLECTIONS

- There are other foundations that can contribute to similar projects.
- I will continue to apply for financial support to be able to maintain the Treasure Room.
- I recommend that more healthcare units try to expand their "gift box". Even if it's not possible to create an entire room, it's possible to expand and adapt the concept with minimal resources.
- In Stockholm, we are fortunate to receive financial support from the Astrid Lindgren Foundation, but there are other foundations that can contribute to similar projects.

Not an actual patient

Horse Activity Group

BEST PRACTICE SHARING

COUNTRY
Finland

ACTIVITY OWNER
Laura Närhi
Helsinki-Uusimaa Epilepsy Association

BACKGROUND

- We are a small epilepsy association, with a number of volunteers, who work with one paid employee.
- The Uusimaa region has 26 towns and cities and that is our working area from where we try to reach people with epilepsy and their family members.
- The horse activity is for children and young people with epilepsy.
- We wanted to offer the possibility to spend time with horses, and experience success in the stable environment with peer support from other children and young people.

APPROACH

- Small group size: two to four participants.
- One employee and one to two volunteers helping for safety reasons.
- The activity does not include riding - we spend time with the horses in the stable.
- The activity is one and a half to two hours.
- Our group needs a calm environment and the stable owner has arranged that for us (there are no other customers at the same time).

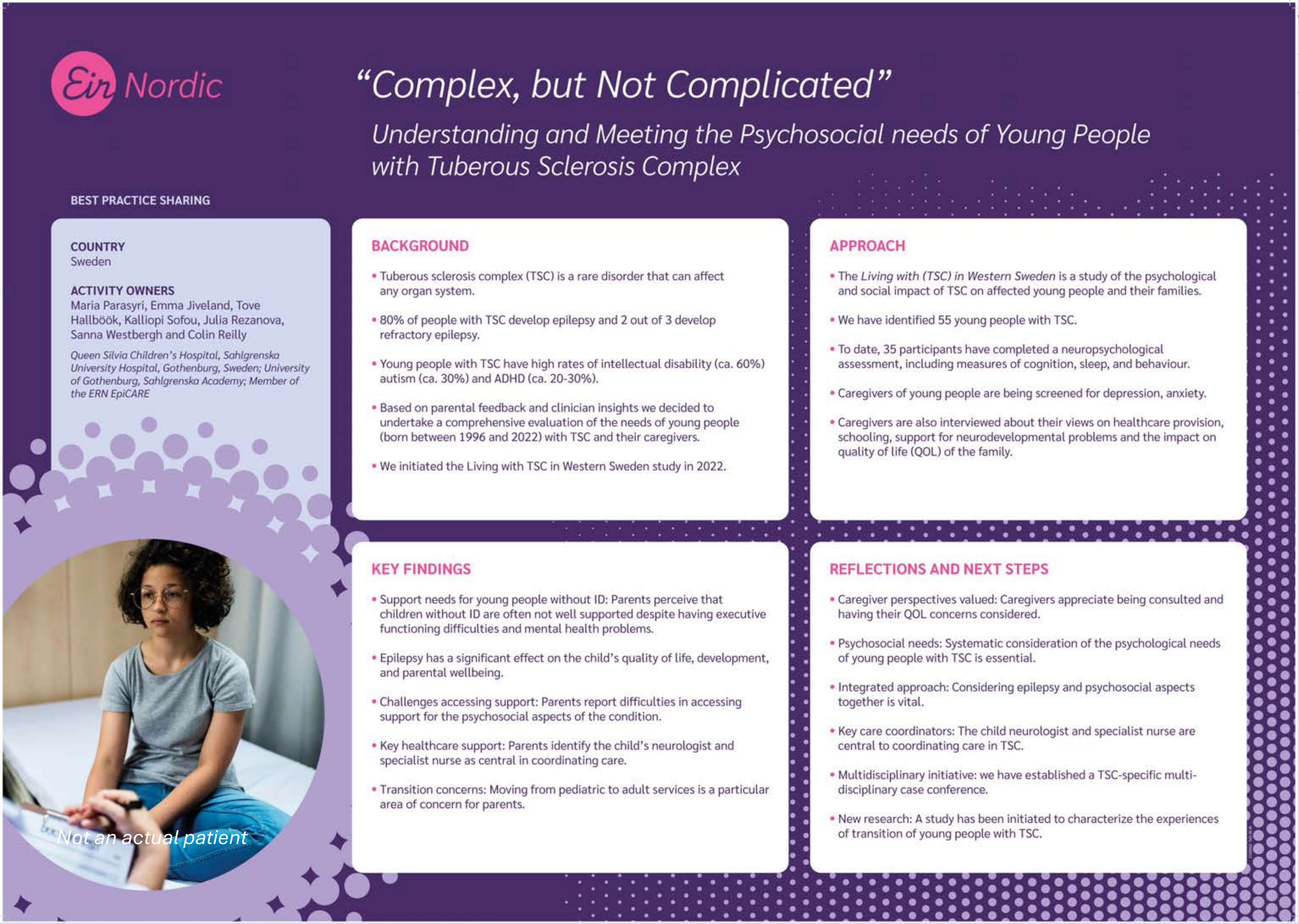
OUTCOMES

What we actually do?

- We learn how to behave around horses and the rules of the stable environment.
- We get the horse to the “cleaning spot” from the ”pihatto” (which means a horse shed where the horses are kept unchained).
- We always clean the horse with the brush and pet it, and we spend time with the horse.
- We lead the horse around the stable environment.
- We learn how to clean the horse equipment.
- We feed the stable bunnies and pet the stable cats.
- We always have a little snack-time in the end of the group. It´s nice to sit down and chat a little bit about what we have experienced today.

NEXT STEPS & REFLECTIONS

- It´s important to find a good stable with suitable horses. We found a nice place and old and calm horse from Tuusula, Lähderanta Stable, and this stable has been our cooperation partner.
- Our resources are not big, so we cannot offer the Horse Activity Group every year.
- The feedback has been pretty good. The group has offered to learn more about horses and to add courage and self-belief.
- We have young people who have started a riding hobby after being in the Horse Activity Group.



“Complex, but Not Complicated”

Understanding and Meeting the Psychosocial needs of Young People with Tuberous Sclerosis Complex

BEST PRACTICE SHARING

COUNTRY
Sweden

ACTIVITY OWNERS
Maria Parasyri, Emma Jiveland, Tove Hallböök, Kalliopi Sofou, Julia Rezanova, Sanna Westbergh and Colin Reilly

Queen Silvia Children’s Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden; University of Gothenburg, Sahlgrenska Academy; Member of the ERN EpiCARE

Not an actual patient

BACKGROUND

- Tuberous sclerosis complex (TSC) is a rare disorder that can affect any organ system.
- 80% of people with TSC develop epilepsy and 2 out of 3 develop refractory epilepsy.
- Young people with TSC have high rates of intellectual disability (ca. 60%) autism (ca. 30%) and ADHD (ca. 20-30%).
- Based on parental feedback and clinician insights we decided to undertake a comprehensive evaluation of the needs of young people (born between 1996 and 2022) with TSC and their caregivers.
- We initiated the Living with TSC in Western Sweden study in 2022.

APPROACH

- The *Living with (TSC) in Western Sweden* is a study of the psychological and social impact of TSC on affected young people and their families.
- We have identified 55 young people with TSC.
- To date, 35 participants have completed a neuropsychological assessment, including measures of cognition, sleep, and behaviour.
- Caregivers of young people are being screened for depression, anxiety.
- Caregivers are also interviewed about their views on healthcare provision, schooling, support for neurodevelopmental problems and the impact on quality of life (QOL) of the family.

KEY FINDINGS

- Support needs for young people without ID: Parents perceive that children without ID are often not well supported despite having executive functioning difficulties and mental health problems.
- Epilepsy has a significant effect on the child’s quality of life, development, and parental wellbeing.
- Challenges accessing support: Parents report difficulties in accessing support for the psychosocial aspects of the condition.
- Key healthcare support: Parents identify the child’s neurologist and specialist nurse as central in coordinating care.
- Transition concerns: Moving from pediatric to adult services is a particular area of concern for parents.

REFLECTIONS AND NEXT STEPS

- Caregiver perspectives valued: Caregivers appreciate being consulted and having their QOL concerns considered.
- Psychosocial needs: Systematic consideration of the psychological needs of young people with TSC is essential.
- Integrated approach: Considering epilepsy and psychosocial aspects together is vital.
- Key care coordinators: The child neurologist and specialist nurse are central to coordinating care in TSC.
- Multidisciplinary initiative: we have established a TSC-specific multi-disciplinary case conference.
- New research: A study has been initiated to characterize the experiences of transition of young people with TSC.

Further Education in Epilepsy, health supervision and quality improvement in practice

A collaboration between OsloMet – Oslo Metropolitan University and the National Centre for Epilepsy – SSE

BEST PRACTICE SHARING

COUNTRY
Norway

ACTIVITY OWNERS
Ellen Kjendbakke, master in education science. Head of education, National Centre of epilepsy, Oslo university hospital

BACKGROUND

- Local government in Norway provide care for patients with complex forms of epilepsy, and there is a high demand for epilepsy-related knowledge within health and care services.
- To ensure employees are professionally trained to deliver evidence-based services, continuous knowledge updates are essential throughout their careers.
- This education program is designed to meet the need for professional competence among health and social care professionals.
- The focus is on improving the quality of life and service offerings for people living with epilepsy.
- Delivered in a fully digital format, the program ensures equal and flexible access to education across Norway.
- The National Centre for Epilepsy has collaborated with university colleges on this further education program since 2006. Today it is OsloMet – Oslo Metropolitan University.

The education was initiated for employees in health and care services, (re)habilitation services, outpatient clinics, as well as educational staff working with students who have epilepsy.

APPROACH

- This further education program has been developed through close collaboration between the professional field, the National Centre for Epilepsy (SSE), a broadly composed reference group, students, and OsloMet – Oslo Metropolitan University.
- The program is delivered entirely online and includes webinars via Zoom during both the autumn and spring semesters. Healthcare professionals from SSE contribute to the teaching, ensuring that students receive up-to-date knowledge in the field of epilepsy, including the latest developments from clinical practice.
- Structured as a part-time course, the program offers a study progression of 15 ECTS credits per semester. Students complete exams in both semesters and engage in group sessions with assignments between webinars.
- A key focus of the program is to create an interactive learning environment. It is beneficial for students to integrate their everyday work experiences into the learning process.
- On average, 20–25 students enroll in the program each year, creating a manageable and engaging learning community.

OUTCOMES

- Most of the students enrolled in this further education program, work in supported housing for individuals with intellectual disabilities.
- This ensures that the users/patients in these institutions benefit from having competent and knowledgeable staff around them, contributing to both safety and quality of life.
- Upon completion of the program, students will be well equipped to support users/patients with various forms of epilepsy and complex needs.
- This approach benefits the students' workplaces, as the knowledge and skills gained through the program are brought directly into practice.

NEXT STEPS & REFLECTIONS

- We will update the digital learning resource in spring 2026.
- The program will be promoted to all supported housing units, hospitals, and habilitation services that work with individuals with epilepsy.

Two key factors for success:

- Strong connection to the health and care services (primary care, specialist care, and school health services), such as the National Centre for Epilepsy (SSE) in this case.
- A well-developed digital e-learning resource with videos, texts, and assignments. This stimulates experience sharing and encourages participants to practice sharing their expertise through teaching at their own workplace.

Adapting admissions for vulnerable patients at the National Centre for Epilepsy

BEST PRACTICE SHARING

COUNTRY
Norway

ACTIVITY OWNER
Vibeke Snarset, nurse and department head Ward 2, SSE

BACKGROUND

- National Centre for Epilepsy (SSE) admits patients from all over Norway. Previously, SSE experienced that many patients had great difficulty completing the journey, the stay (new environment), and/or the EEG examination.
- A model was developed to prepare the patient, caregivers, and SSE as best as possible. When admission is individualized for each person, assessment/treatment can be carried out without excessive strain on vulnerable patients.
- It can be challenging for these patients to tolerate having something on their head (EEG); many must train for it a long time in advance (own adaptation program). Blood tests can also be extremely demanding.
- In some cases, caregivers and doctors have doubted whether assessment/treatment at SSE for some patients could be carried out, due to the patient's functional level. As a result, this patient group has not received the necessary assessment/treatment.
- The patient group is characterized, among other things, by:
  - Intellectual disabilities and/or autism spectrum disorders
  - With/without additional psychiatric difficulties
  - Severe behavioral problems/self-harm
  - Major medical challenges

OUTCOMES

- By using the structured telephone assessment in advance, we facilitate so that patients more easily manage to complete the admission with EEG.
- The reason for referral becomes easier to answer correctly if the patients are able to complete EEG, advanced blood tests, and are observed by experienced staff in Ward 2. The patients then receive more optimal treatment.
- Caregivers around the patient receive thorough training in what epilepsy is, seizure observation, seizure management, types of seizures, seizure documentation, treatment, acute seizure management, medications, and environmental conditions. Various tools have been developed to support such training.

APPROACH

- Before admission, a structured telephone assessment is carried out to prepare the patient, caregivers, and SSE as best as possible so that the admission can be individualized and the assessment/treatment can be more easily completed. Many patients arrive with questions such as "what is what – epileptic seizure or behaviour?" Performing EEG and other tests can help answer the questions raised in the referral.
- In the structured assessment conversation, it may also emerge what kind of training, guidance, or information the caregivers need. This is central throughout the admission and afterward to increase epilepsy competence around the patients.
- Some patients cannot cope with an admission at SSE; these are offered outpatient treatment at home. Experienced SSE staff travel to the patient's home and stay for 2 days, conduct EEG, observe, guide, and provide 3 hours of dialogue-based teaching. A digital summary is then carried out with a doctor and nurse from SSE, the patient's caregivers, the general practitioner, and the referring unit to discuss which measures should be implemented after the assessment/treatment.

NEXT STEPS & REFLECTIONS

- It is very important that the admission/outpatient treatment is adapted as individually as possible, so that the patient has a good experience of the assessment/treatment, avoiding stress and resistance to further assessments or treatments. This also allows the reason for referral to be answered more accurately.
- The vast majority of patients have completed the assessment/treatment at SSE. Caregivers report that it is possible to prepare patients for examinations/activities they previously thought were impossible.
- Structured telephone assessments have been introduced throughout SSE to varying degrees; these are continuously evaluated and improved. Outpatient treatment as an option is desired to be expanded to other vulnerable patient groups, for example children.
- Continuous work is being done to increase epilepsy competence among the caregivers around the patients.

Highly specialized clinic for children with refractory epilepsy

BEST PRACTICE SHARING

COUNTRY
Sweden

ACTIVITY OWNER
Matilda Modigh

BACKGROUND

- In 2018, I co-founded a highly specialized clinic for children with refractory epilepsy with pediatric neurologist Tommy Stödberg.
- The clinic began with one contact nurse (myself) and has since expanded to two nurses.
- We now care for around 200 patients that have direct access to us for quick assistance and advice.
- This helps us avoid sending patients through the emergency department.
- Provides more coordinated care.
- Children and adolescents with refractory epilepsy, many of whom have comorbidities such as intellectual disabilities.

APPROACH

- Involves experienced healthcare professionals.
- Identified what the patients and families felt was important to feel seen and listened to.
- Children and adolescents with refractory epilepsy, many of whom have comorbidities such as intellectual disabilities.
- Families have our direct phone number and the ability to contact us digitally via chat, Monday to Friday.
- Close collaboration with the inpatient ward to, in many cases, avoid ending up in the emergency department.

OUTCOMES

- Provides more coordinated care.
- The patient and their family feel seen.
- Comfort and safety.


Knowledge

Experiences

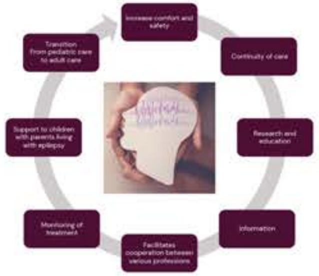
Pedagogy

Collaboration

Holistic approach

NEXT STEPS & REFLECTIONS

- Spread awareness so that other hospitals can implement the same type of clinic.
- This has made a difference for the patient and their family.
- It has not led to more calls from the patients and their families.
- Better-structured care.


Increase comfort and safety

Continuity of care

Research and education

Information

Facilitates cooperation between various professions

Monitoring of treatment

Support to children with parents living with epilepsy

Transition From pediatric care to adult care

Eir Nordic

TSC Summer Camp

BEST PRACTICE SHARING

COUNTRY
Sweden

ACTIVITY OWNER
Annika Hallberg Juhlin

BACKGROUND

Living with Tuberous Sclerosis Complex (TSC) affects the entire family.

- Tuberous Sclerosis Complex (TSC) is a genetic condition that cause benign tumors in many different organs like the brain, skin, and kidneys. Most people with TSC have epilepsy, and many also live with autism, intellectual disability, and physical impairments. Symptoms and severity vary widely. This often makes it difficult for families to take part in vacations or leisure activities that everyone can truly enjoy together.
- Many families also describe feeling "different" or "stared at" in public. Meeting others who share similar experiences can change that.
- Except all fun activities and the good feeling of inclusivness, the camp creates space for exchange of ideas, hope, and practical insights.
- The TSC Summer Camp is open to all families living with TSC who are members of the TSC Patient Association – from those newly diagnosed to those who have lived with TSC in the family for many years. The camp includes activities for all family members, across all age groups, of course including the person with TSC and, if needed, their assistents.

REFLECTIONS AND LEARNINGS

- Secure funding well in advance – it always takes more time than expected.
- The venue is crucial and we recommend to prebook well in advance!
- Provide varied and engaging entertainment and activities.
- Build a strong, structured program.
- Learn from previous years and reuse successful materials and activities.
- Delegate responsibilities for the camp activities.
- Organizing the camp is highly time-consuming, and the lead organizer does this work outside of normal hours – while also being a parent of a child with TSC. To share the load, we encourage participants to take responsibility for activities where they have experience or interest.
- Recognise extend of work and coordination required, not only before the camp, but also during the camp. Delegate responsibility and use a common platform for different groups to communicate, we used closed FB-groups one for each: parents, assistants and siblings.

OUTCOMES

- The TSC Summer Camp has become a cherished annual event for families affected by TSC – a rare opportunity to connect, share experiences, and enjoy meaningful activities together in a supportive and understanding environment. It's an occasion families truly look forward to each year.

APPROACH

How to Apply for Funding

- The camp is expensive to run, so to keep participation costs low, the organization actively seeks external funding. The most significant contributor is Socialstyrelsen (The National Board of Health and Welfare), which recognizes the camp's positive impact on families who are hard hit by TSC. Each year, we follow up closely with Socialstyrelsen to help secure funding for the following year.
- To secure funding for the camp, it's essential to confirm support from Socialstyrelsen, which so far has been the largest contributor. At the same time, it's wise to apply to several other organizations or companies. These are often more likely to approve grants when costs are shared among multiple funders.

Find the right venue and start registration

- Once the majority of funds have been secured, we continue fundraising while also opening registration through the TSC Sverige website.
- Finding the right venue is crucial – we look for:
  - Facilities with easy access to a variety of activities and of course accessible with wheelchair.
  - The camp should be held at a place we can use exclusively. Our best experiences have been in small cabin villages, which allow for more spontaneous gatherings and a stronger sense of community than staying in separate hotel rooms.
  - Staff who are flexible, supportive, and willing to learn (we provide training in advance).

Personal Assistants

Because the camp welcomes entire families, we rely on dedicated assistance for care and activities. Finding personal assistants can be challenging. Participants often support each other, for example share tips about assistants you know who might be interested in working with someone else during the camp.

About the program

The organizer prepares a detailed schedule with activities for all participants: persons with TSC, parents, siblings, and assistants. Each sibling group has dedicated leaders to ensure inclusion and engagement. The program may include a guest speaker for the parent group and workshops tailored for siblings.

TSC Summer Camp

BEST PRACTICE SHARING

COUNTRY
Sweden

ACTIVITY OWNER
Annika Hallberg Juhlin

FÖRSTA GÅNGEN – OCH DEFINITIVT INTE DEN SISTA!

Vi är helt nya i TSC Sverige och hade aldrig tidigare varit med på något arrangemang. När vi anmälde oss till familjelägret på Isaberg visste vi inte riktigt vad vi skulle förvänta oss. Vår dotter Isabella är bara två och ett halvt år gammal, och vi var lite oroliga för att hon kanske skulle vara för liten för att riktigt passa in eller kunna delta i aktiviteterna.

Men redan första dagen insåg vi att den oron var helt obefogad. Vi blev så otroligt fint mottagna – både av arrangörerna och av alla andra familjer. Det var en varm och inkluderande stämning från första stund, och Isabella hade det helt fantastiskt. Hon lekte med både andra barn med diagnos, syskon och assistenter, och vi föräldrar fick för första gången verkligen känna att vi inte var ensamma.

Det allra viktigaste för oss var kanske just de där samtalen. Att få sitta ner med andra föräldrar som vet hur det känns, som har liknande erfarenheter, tankar och känslor. Det går knappt att beskriva hur mycket det betyder.

Så till dig som kanske funderar på att åka nästa gång men känner dig osäker – gör det. Vi förstår känslan, vi hade den själva. Men vi lovar: du kommer inte att ångra dig. Det här lägret var något av det bästa vi har gjort som familj. Vi åkte hem med nya vänner, ny kunskap – och en stark känsla av att vi faktiskt tillhör något större.

Ni kan räkna med att vi kommer tillbaka – lite mer rutinerade, ännu mer peppade och redo att välkomna nästa förstagångsfamilj med öppna armar, ett leende och kanske ett och annat kajaktips (lyssna inte på dem i så fall).

Vi är ganska nya med diagnosen: så bra att få prata med andra föräldrar här. Vi var inte redo att ta emot all info vi fick på sjukhuset. Skapade värdefulla kontakter och vänner. Ser fram emot nästa år redan.

Det finns så lite tid till samtal i det vanliga livet. Här fick syskonet fokus och vi fick mycket fin tid tillsammans. Samtidigt visste jag att mitt barn med TSC var på annan rolig aktivitet i goda händer.

Bra fördelning mellan ett par viktiga föreläsningar med ny kunskap om TSC och semesterkänslan av att faktiskt få antingen slappna av eller välja någon rolig aktivitet – det är vi verkligen inte bortskämda med.

The association is so important for us and these camps has meant so much. Cannot imagine how we could cope without.

Annika är helt fantasktisk ♡

Gemenskap - de får en KOMPIS som inte är annorlunda än dem! Även om man bor på olika ställen i landet så är detta en väldigt viktig kompis-träff.

Vilken kunskapskalla! Att både få och ge små tips i vardagen kan betyda så mycket!

Här ges en så fin möjlighet att skapa riktiga vänskapsband.

02

Workshop output

Eir Nordic

Theme 1 | *Making Collaboration Work*

Key take-aways

Lack of resources is making it difficult for collaboration to work.

These resource shortages are creating a knock-on effect on collaboration, contributing to a **challenging working culture** and a high rate of staff turnover and increasing knowledge gaps.

The need for more regular **knowledge-sharing events**, such as Eir Nordic, was highlighted as a key priority to strengthening collaboration.

Challenges and barriers

Limited resources – Both human and financial constraints were highlighted as the largest barrier. Limited resources can contribute to a challenging working culture and a high rate of staff turnover.

Information and knowledge gaps – A lack of understanding of the broader care pathway and knowledge gaps amongst carers makes it difficult for collaboration to happen

Limited platforms for knowledge sharing – Within each country and across the Nordics there are limited initiatives dedicated to collaboration and best practice sharing. We lack platforms to start the dialogue and work closer together

Possible action

There's widespread consensus amongst participants that there is a need for more regular knowledge sharing and the exchange of best practices. Opportunity to build more forums and events for people with vested interest to engage in dialogued – also across care pathways (patients, families, care homes, HCPs, patient organisations)

Enhancing knowledge sharing would support individuals and organisations to identify key contacts, bridge barriers, raise awareness of challenges, and learn from successful initiatives.

Some also suggested the possibility of developing an e-learning program/online resource to share knowledge across the Nordics

Meetings and Events	● ● ● ● ● ● ● ● ●
Online Professional Forums	● ●
Guidelines and policy	● ●
Collaboration culture	● ● ●
Access to practitioners	●
Resources	● ● ●
Leaders	● ● ● ● ● ● ●

Where is the biggest opportunity for impact? Participant rating across areas

Theme 2 | *Increasing awareness*

Key take-aways

Lack of resources is making it hard to deliver high-quality care for those who need it most.

There is a need for **largescale campaigns** to raise awareness, educate and force this issue into the public conversation - both amongst **policy makers, health care professionals and the general public**

Any campaign activity should **rely heavily on SoMe** to reach a wider demographic, and the **patient association would be a powerful collaborator** to get the message out

Challenges and barriers

Limited resources – Both human and financial constraints were highlighted as major barriers. The lack of dedicated resources makes it difficult to focus on activities beyond immediate care, including raising awareness.

Low public awareness – Limited understanding among the general public about the seriousness of epilepsy and intellectual disability makes it harder to draw attention to the issue and combat stigma.

Lack of visibility in public discourse – The difficulty of bringing these challenges into the broader public conversation limits political engagement and, in turn, progress in public health policy.

Possible action

There's general agreement amongst participants that there is an urgent need for widescale, national campaigns to raise awareness for those living with epilepsy and intellectual disability and force their stories into the public conversation.

Awareness campaigns should be directed towards different target audiences. Beyond the general public - policy makers and healthcare professionals including assistants and care givers were identified as key audiences.

The discussions highlighted the importance of recognizing the vital role played by volunteers. Their stories and perspectives are powerful levers for raising awareness. There was also a general agreement that epilepsy associations should collaborate to get the message out.

There were many great ideas on the practicalities of campaigns. There was widespread agreement that it should include heavy use social media (including TikTok) to reach a different demographics.

One point that raised conversation was the idea of a figurehead for the movement or a "Greta Thunberg" to speak for epilepsy.

Awareness campaign	● ● ● ● ● ● ● ● ●
Community engagement	● ● ● ●
Political lobbying	● ● ● ●
Partnerships	● ● ●
Sponsorships and patronage	● ●
Education	● ● ● ● ● ● ● ● ●

Where is the biggest opportunity for impact? Participant rating across areas

Theme 3 |
Quality of Life

Key take-aways

Multiple barriers stand in the way of improving quality of life. Some are local and can be addressed through better access to information and stronger sharing of best practices, while others are systemic — such as policy limitations and geographical disparities — and will require political action.

Participants proposed creating a shared “bank” of best practices to strengthen collaboration and knowledge exchange across the Nordic epilepsy organisations.

It’s clear that continued effort and cooperation are needed to identify and implement effective solutions that truly enhance quality of life for this community.

Challenges and barriers

Lack of education and training was seen as a key barrier. Many care staff lack the knowledge and confidence needed to provide optimal care. This often leads to uncertainty or fear, which can hold them back from trying new approaches or activities.

Diagnostic overshadowing was highlighted as a major challenge. People living with epilepsy and intellectual disability often face multiple health issues, where other conditions may take precedence - leaving epilepsy insufficiently addressed.

Health policy limitations were discussed as another barrier. Across the Nordics, political focus on enabling people to “stay at home” for as long as possible can unintentionally stand in the way of ensuring adequate, specialised care.

Limited best practice sharing remains an issue. While there are pockets of excellence, these examples rarely reach the wider community. Participants agreed that initiatives focused on sharing best practices should be prioritised.

Transition from child to adult care was raised by all groups. Vital information, routines, and lived experience are often lost during this transition, which can significantly impact wellbeing and continuity of care.

Geographical disparities were also noted. In some regions, limited access to resources, expertise, or education directly affects the quality of care and quality of life.

Action

There were suggestions from the participants about creating a best practices "bank", a central resource that epilepsy organizations could use to ensure the best quality of life care.

Despite there being strong consensus on some of the major barriers, it's clear that there's still much to be done to identify and implement the next steps.

HCP access and support	●
Mental health support and therapy	● ● ● ● ●
Family support	● ● ● ● ● ●
Education	● ● ● ● ● ● ● ● ● ●
Medical research	● ● ● ●
Communication	● ● ● ● ● ● ● ●
Transition focus	● ● ● ● ●

Where is the biggest opportunity for impact? Participant rating across areas

Eir Nordic

Thank you!