

DRAVET SYNDROME

# Burden and Stigma ... *a patient`s voice*

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**dravet**  
**suisse**



# 1:22.000 Children



*One child in 22.000 is statistically affected by Dravet Syndrome...*

## What does that mean?

- Each diagnosis calls into question opportunities the life offers, dreams, adventures, lighthearted childhood and exciting adolescent years ... and often families and friendships.
- Every child bravely goes through seizures, uncertainty, the side effects of medication, the rejection of society, etc. ...

## But... we are lucky!



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## Because we have a diagnosis!



# 1:22.000 Children



## What does that mean to have a diagnosis?

- We can network with other associations and families...
- We have a name of the disease and usually a number in the catalogue of Birth Defects, ... which means you have the chance - **never the guarantee** - to get:
  - *support material like nappies, orthoses, wheelchair, helmet, corset, night control, oxygen support etc. ... (the list is much longer)*
  - *financial support like pension, assistance allowance etc. (**bar is high!**) ...*
  - *Different therapies*
  - *Medication covered by the IV*
- Research and participation in studies become possible...

# The burden...





# Seizures ...



## Seizure types *(can occur individually or in combination):*

- generalised, i.e. affecting the whole brain
- focal, i.e. affecting individual areas of the brain
- tonic, i.e. convulsive
- atonic, i.e. flaccid
- clonic, i.e. rhythmically twitching
- Myoclonia, i.e. non-rhythmic muscle twitching while conscious
- Absences, i.e. states of absences with pausing of movement
- complex-focal, i.e. affecting several areas of the brain
- Seizures with blinking
- Falling seizures
- **Status Epilepticus!**





# Comorbidities

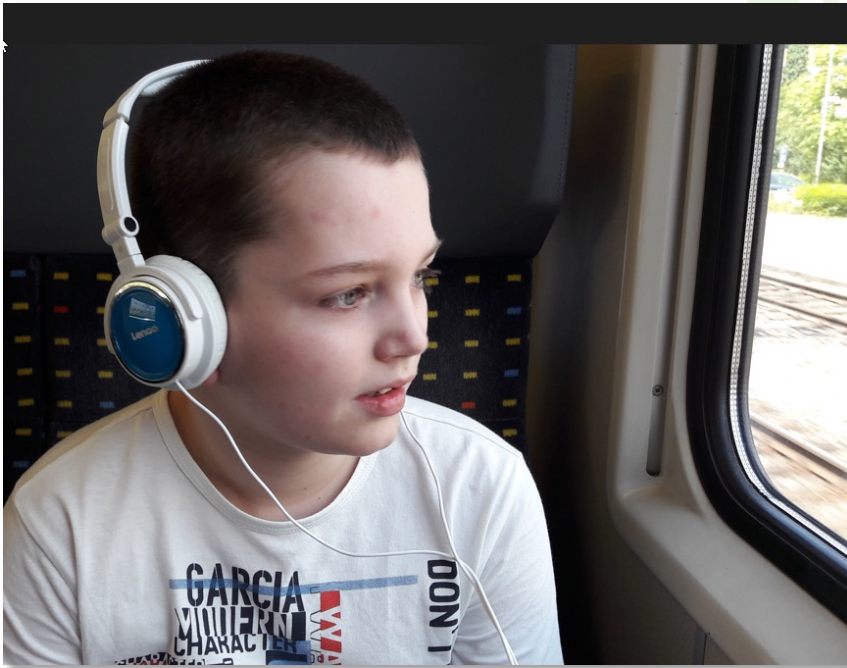
- Behavioural problems
- Attention disorders
- Delayed speech development
- Ataxia
- Orthopaedic problems
- Motor and balance problems
- Hypotonia
- Sleep disorders
- Chronic infections
- Perceptual disorders

*... and much more.*





# Everyday life...



- 1) 24h-observation / care
- 2) When joy become the enemy
- 3) Fear
- 4) „Battling“ many fronts
- 5) Social security / IV
- 6) Difficulties in social life
- 7) Holidays? Holidays!



# 1) 24h-observation / care

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- **A seizure can occur anytime and anywhere**
- A parent is always there: ... having a bath, shower, climbing stairs, eating, drinking, playing...
- We have a very well trained „eye“ for the surroundings...
- We know the physical signs...
- We have a very light sleep...
- **Sometimes we also hear „ghosts“...**

## 2) When joy becomes the enemy...

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### Typical seizure triggers include ... excitement:

- Physical exertion → playing, running, climbing, swimming
- Being tired
- Emotions like overstimulation (i.e. many people), anger, annoyance, stress, and unfortunately ... joy...



## 2) When joy becomes the enemy...

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# 3) Fear

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## Presence...

- Will the child get on the new bus driver tomorrow?
- The weekend will be hot...
- Will the shopping go well?
- Will the child tolerate the Corona vaccination?
- What will we do if there is another shortage of medication?

...



**For the child!  
Always!**

## Future...

- What if something happens to us parents?
- How can we protect our basic financial stability?
- Where will my child live later?
- Will we stay healthy?
- Have we considered / thought of everything? What do we need to know?

...

# The stigma...





## 4) „Battling“ at many fronts



### Schooling / Day Care



- We parents know that generally our children will not attend a regular school and will not have a regular education
- However... yet we want our children to be supported and to use their full potential
- Finding the right day care is very difficult → Aspiration and promises of the different institutions often sound very good and like an individual support ... we talk about children, whom`s needs could not be more different
- Reality is very often (due to cost, resources etc.) a strongly standardized approach
- We always have to ask, convince, battle insist on many things....

## 4) „Battling“ at many fronts



### Therapies & Support



- The **first hurdle** is to get the required therapies approved:
  - *depending on the Birth Defect (speech therapy, occupational therapy, physiotherapy, hippotherapy, orthoses, rehab buggy, wheelchair)*
  - *IV processes often are complicated and very formal (right form? right wording? Parents need to check whether all facts have been recorded and considered)*
- The **second hurdle** is to integrate the therapies into everyday life...
  - Find slots when you are full-time employed
  - Organization of transport, parents have to wait there...

## 5) Social security / IV...

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*... or our struggle with institutions, authorities and others:*

- Therapies and aids are always linked to the “confirmed” Birth Defect
- **Rare diseases often fall between “tree and bark” as a 100% clear allocation to the catalogue of Birth Defects is difficult and not straight forward**
- The handling is extremely different between the cantonal IV offices
- Processing times take usually very long
- Parents often feel like a petitioner...
- Processes are kept very complex → *“You can apply for an order that is appealable.”*
- **Assessments by the IV are done in a generic way by ticking boxes, lists, catalogues... →**

## 5) Social security / IV...

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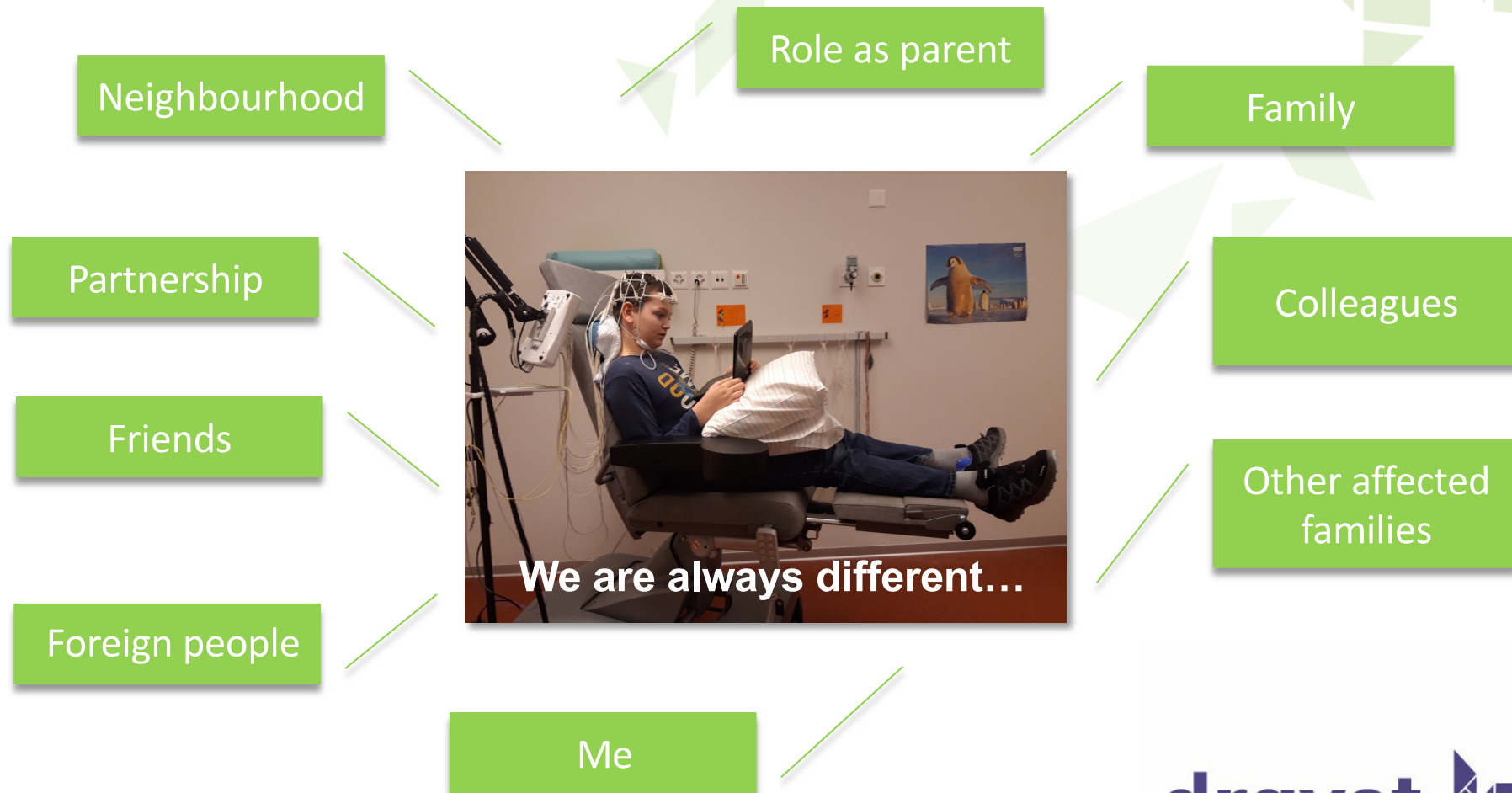


### Not considered are typically:

- Times you spend to care for the child during night time... e.g. after an epileptic seizure that has caused paralysis of the arms and/or legs ... or just for sleep disturbances
- Times you wait for your child during therapy appointments
- Times you are searching for therapies, material, and you are writing letters/e-mails to the different stakeholders...
- Times you cannot spend for cultural and social events, which are normal to parents with healthy children ... meeting friends, cinema, theatre, wellness, hobbies and so much more...
- **Far too often a lawyer is needed! Which increases the feeling of “not being entitled”!**

## 6) Difficulties in social life

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# Holidays? Holidays!



## Being well, well organized:

- Enough medicines, nappies, and other support material!
- Plan space for wheelchair and lower leg orthoses
- How do we travel? What is possible?
- What awaits us at the holiday destination?
- Can we go to a restaurant? *We ignore the stares!*



# And ... what about us parents?

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- Long process to accept the given → emotional balance act!
- Parents are (officially) responsible for their children until the age of 18... however, time without the kids (to read a book?) is possible much earlier than this...
- We parents of special children have very limited me-time, career opportunities, social contacts, mental balance, ... and much more...

**What we need is not pity, but understanding, support, relief ...**

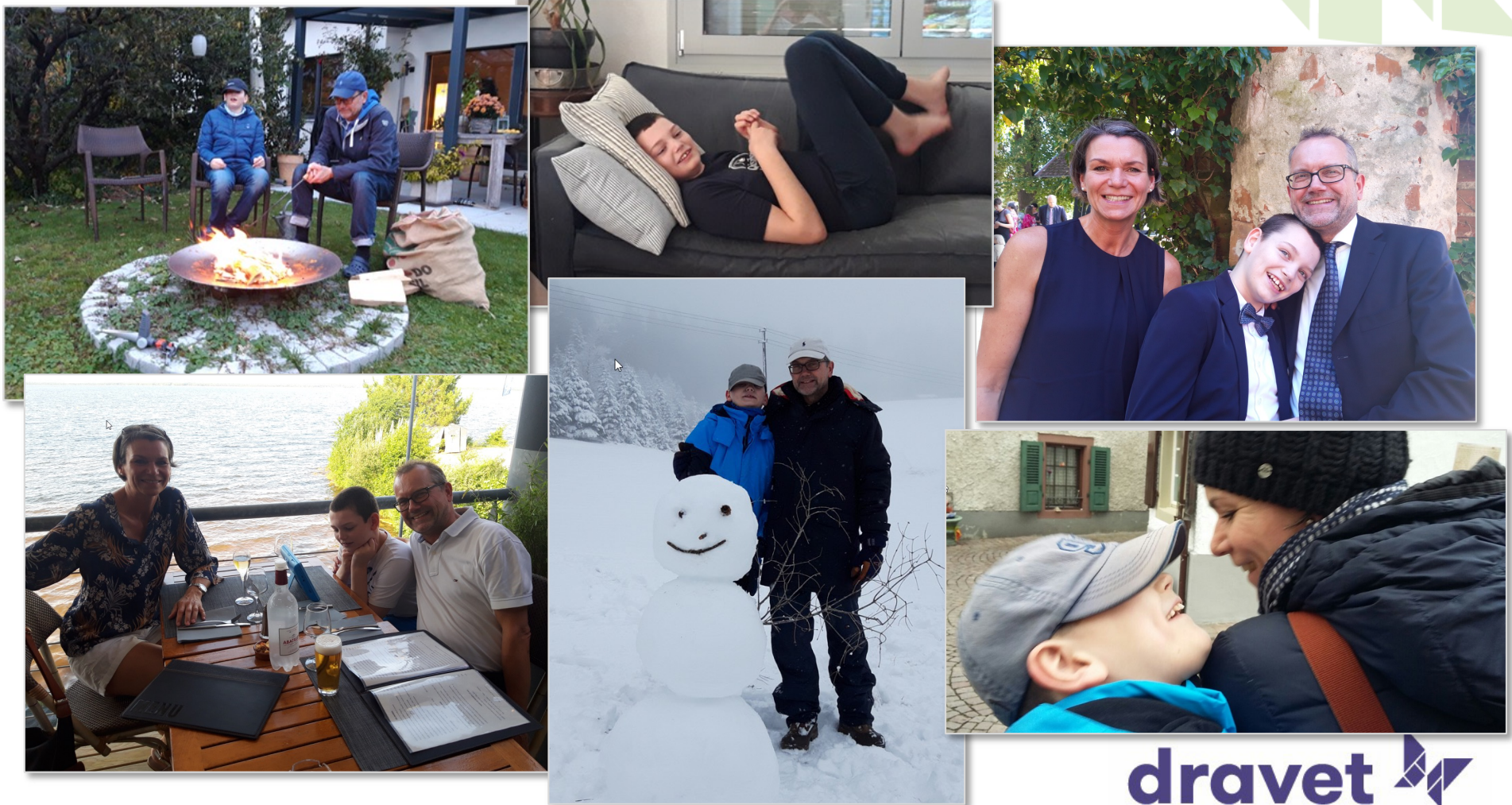
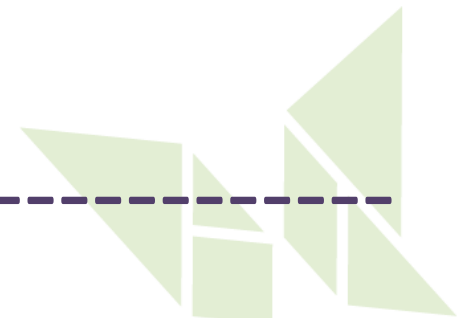
**But beside Burden  
and Stigma...**





# We are a great family with a lovely son...

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**dravet**   
**suisse**

