

*What needs to be done to
provide minimal **Standards**
of Care across Europe*

Definition and Problems

2 typical Cases

A concept

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Standard of Care

- Definition -

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What Does the Medical “Standard of Care?”

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To the Editor:

We searched for the exact phrase “standard of care” in the 2009 American Society of Clinical Oncology Annual Meeting Abstracts and found that the term has been used in a total of 70 abstracts covering a wide range of subjects. It is not our

What we mean:

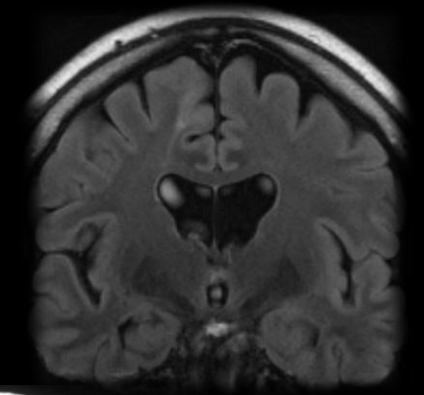
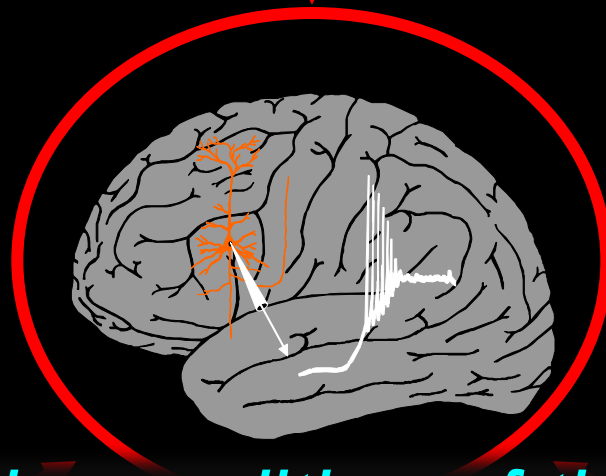
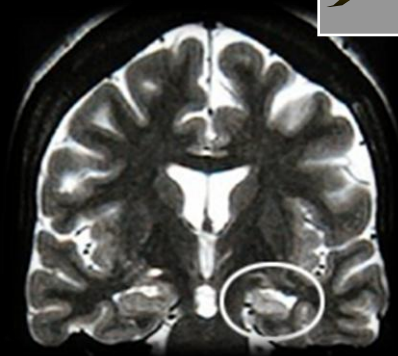
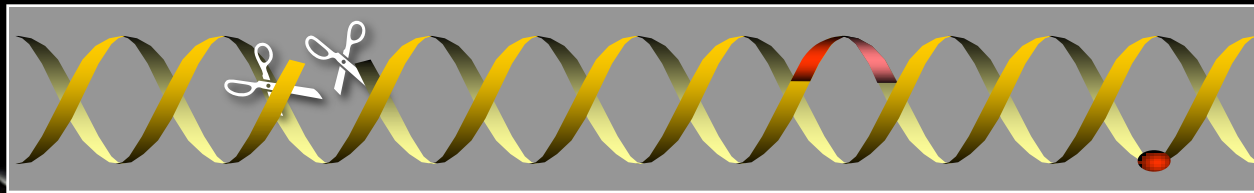
A very good care according to high standards for a reasonable price, taking “proven” scientific results into account.

This is often not operational

There is no medical definition for standard of care, although the term is firmly established in law and is defined as “the caution that a reasonable person in similar circumstances would exercise in providing care to a patient.”¹

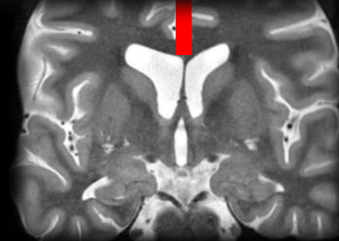
There is no medical definition for standard of care, although the term is firmly established in law and is defined as “the caution that a reasonable person in similar circumstances would exercise in providing care to a patient.”¹ The term represents

The Definition of *Epilepsy*



Chronic condition of the brain

lowest common denominator: epileptic seizures



Standard of Care

- The Epilepsy Problem -

- Epilepsy is one of the most “common neurological diseases”.
- *But it is not a single disease, rather a large group of different aetiologies unified via the leading symptom - the epileptic event.*
- Epilepsy has therefor two facets for diagnosis and treatment:
 - 1) The symptom seizure – is it a epileptic event?
What is the best treatment option for that aspect?**
 - 2) The aetiology of the seizures/epilepsy and its possible consequences**
- *Diagnostic and treatment aspects are highly variable.*
- **Standards of care are therefor very difficult to define.**

Standard of Care

- Requirements -

- What does it need to diagnose an epileptic event as epileptic?
- What does it need to define an epileptic syndrom?
- What does it need to detect the epilepsy specific aetiology?
- *What does it need to decide for an optimal treatment?*
- What does it need to met the health care needs due to comorbidities?

It needs a concept, thorough knowledge and resources

Standard of Care

- Definition -

Epilepsia. 2012 Dec;53(12):2178-85. doi: 10.1111/epi.12002. Epub 2012 Oct 25.

Critical determinants of the epilepsy treatment gap: a cross-national analysis in resource-limited settings.

Meyer AC, Dua T, Boscardin WJ, Escarce JJ, Saxena S, Birbeck GL.

Department of Neurology, University of California, San Francisco, California, USA. meyerac@sfgfgh.ucsf.edu

SIGNIFICANCE: Even among resource-limited regions, people with epilepsy in countries with fewer economic, health care, neurology, and epilepsy-specific resources are more likely to have untreated epilepsy. Community-based epilepsy care programs have improved access to treatment, but in order to decrease the epilepsy-treatment gap, poverty and inequalities of health care, neurology, and epilepsy resources must be dealt with at the local, national, and global levels.

Even the main symptom “seizure” is not treated in some areas

Standard of Care

- How often is it used -

Epilepsia. 2012 Feb;53(2):291-300. doi: 10.1111/j.1528-1167.2011.03353.x. Epub 2012 Jan 5.

Epilepsy is associated with unmet health care needs compared to the general population despite higher health resource utilization--a Canadian population-based study.

Reid AY, Metcalfe A, Patten SB, Wiebe S, Macrodimitris S, Jetté N.

Division of Neurology, Department of Clinical Neurosciences, University of Calgary, Calgary, Alberta, Canada.

- Comparison: epilepsy patient, gen. population, chronic patients (asthma, diabetes, migraine)
- **Epilepsy:** highest rate of hospitalizations and consultations
- Epilepsy patients are more likely to say they had unmet mental care needs
- *Although individuals with epilepsy use more health care services than the general population, this increase appears to be insufficient to address their health care needs.*

Annual Costs per Patient with Epilepsy - European Countries -

Table 27 Annual cost per patient with epilepsy (costs are presented in 2009 Euros).

Country	Direct health care costs	Direct non-medical costs	Indirect costs	Total costs	Year	Reference
Switzerland	5186	n.a.	2831	8017	1990	Gessner et al. (1993)
UK	689	1677	5448	7813	1990	Cockerell et al. (1994)
UK	850	n.a.	2691	3541	1991	Swingler et al. (1994)
France, Germany, UK	3104	409	2555	6068	1993	van Hout et al. (1997)
UK	1044	2375	1777	5196	1993	Jacoby et al. (1998)
France	2640	n.a.	n.a.	2640	1998	(De Zélicourt et al., 2000) – 1st year
France	695	n.a.	n.a.	695	1998	(De Zélicourt et al., 2000) – 2nd year
Italy	1579	n.a.	223	1802	1996	Berto et al. (2000)
Italy	2262	n.a.	n.a.	2262	1998	Guerrini et al. (2001)
Italy	1439	n.a.	n.a.	1439	2000	Tetto et al. (2002)
The Netherlands	3448	901	n.a.	4349	1999	Kotsopoulos et al. (2003)
Italy	1567	n.a.	n.a.	1567	2001	Beghi et al. (2004)
Germany	4493	n.a.	7161	11654	2003	Hamer et al. (2006)
Spain	5566	282	1790	7538	2005	Sancho et al. (2008)

The Case with Early Epilepsy

BLACKOUT 1. März 2007 * BILD-SPORT * Seite 17

Manfred Simon frontal gegen Hauswand Lottner-Manager schwer verletzt

Von PHILLIP ARENS und BENJAMIN SACK
Köln-Lövenich, Brauweiler Straße. Gestern Mittag. Die Ampel an der Kreuzung zeigte grün. Ein Mercedes-Fahrer gab plötzlich Vollgas, riss das Steuer herum. Das Fahrzeug prallte gegen eine Hauswand.

Manfred Simon ist der Fahrer. Er war Sportfunktionär und Musikproduzent. Er war Lidl-Manager. Und er ist Berater und Freund von Kölns Fußballidol Dirk Lottner.

„Epileptischer Anfall!“ sagt die Polizei.

Letztes Jahr hatte Manfred Simon gesundheitliche Probleme. Kardiologisch.

entsprechend besser. „Ich weiß nicht, was da passiert ist. Ich hatte einen totalen Blackout“, sagt er.

Sofort nach dem Unglück fuhr Dirk Lottner ins Krankenhaus. Auch der frühere FC-Spieler Denis Epstein (jetzt RW Essen) besuchte seinen Berater.

Simon war einer der besten Freunde von Jean Lörring. Die Fortuna ist immer noch seine Heimat.

Freunde sind geschockt, aber auch erleichtert, dass Simon Glück im Unglück hatte. Vor ein paar Monaten feierte er seinen 60. Geburtstag. Montag traf sich die „alte Fortuna-Clique“ noch zum Stammtisch.



Bei der BILD-Party im Sommer gern gesehene Gäste: Manfred Simon und Dirk Lottner

Der Aufprall riss Straßenschild und Fußgängerampel

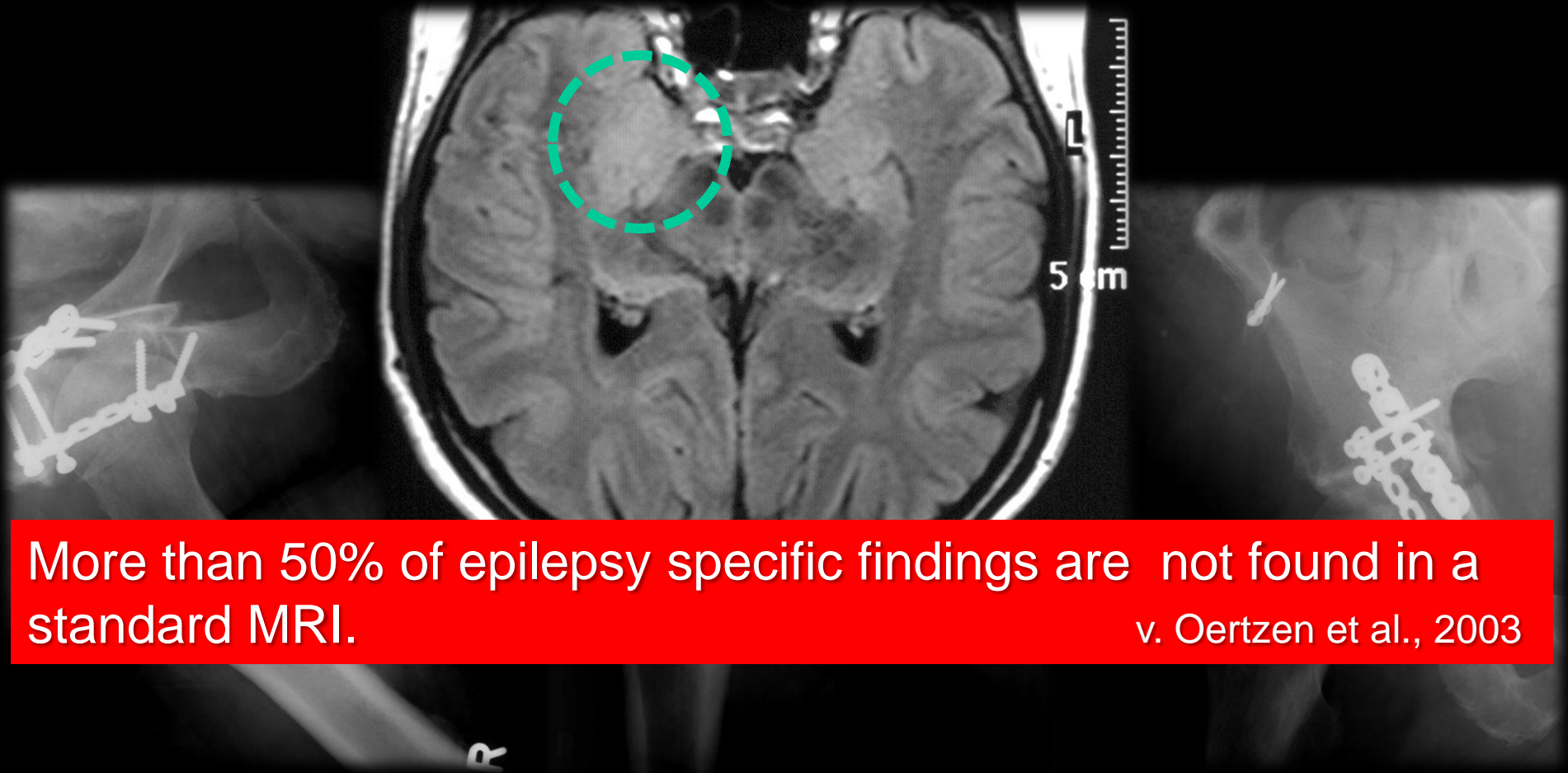
kenhaus verlegt. Gestern Abend ging es Simon den Umständen
Der Kölner Sport wünscht ihm gute Besserung...

... raste gegen die Wand einer...

A Mercedes-driver accelerated suddenly
... An „epileptic seizure“ according to the police

MRI: „no pathological finding“

Optimal Care (Standards of Care)?



More than 50% of epilepsy specific findings are not found in a standard MRI.

v. Oertzen et al., 2003

Standard of Care

- What went wrong? -

- First unprovoked seizure – no treatment (standard of care?)
- No intensive search for aetiology (normal MRI – standard of care?)
- No treatment consideration (standard of care?)

According to German guidelines – the decision was probably OK

- *Aetiology search inadequate. – **seizures have reasons***
- *MRI-standards inadequate – **temporal angulation not adequate.***
- *Possible danger for the patient: **(paraneoplastic) limbic encephalitis***

The Case with Chronic Epilepsy

First seizure with six years (CPS with sec. gen.)

Became criminal with 10 years.

Starting an education as locksmith.

Finished it in prison > 30 years later

1 – 3 seizures every night (CPS)

Pharmacoresistant (7 AED), no aetiology search for more than 5 years (MRI always „normal“), epilepsy surgery never considered

Pat. T. K., m., *11.05.67



The Case with Chronic Epilepsy – Post-Op

Seizure free

Out of prison

Normalized behaviour

Master locksmith

Running a small company

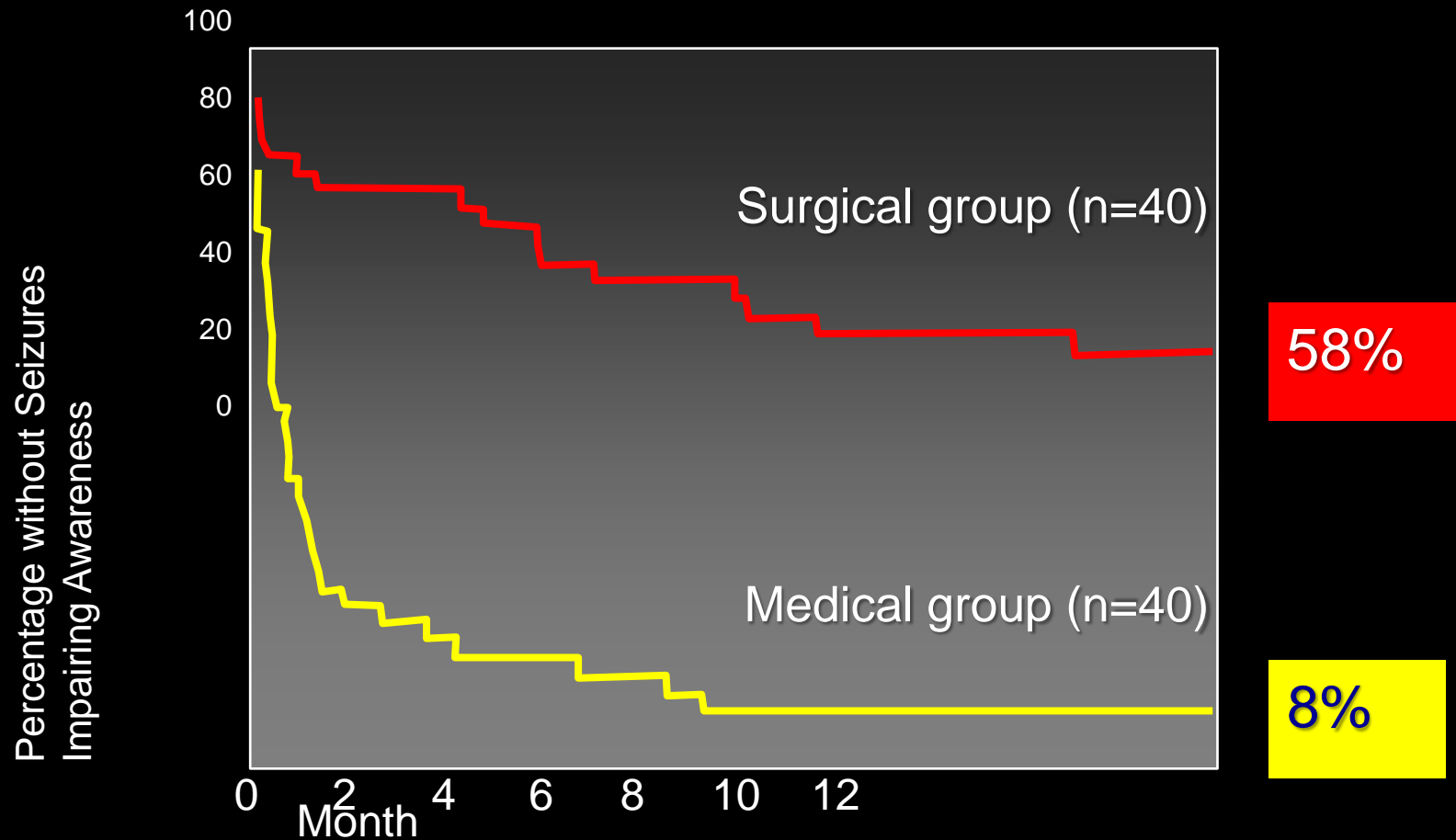
Standard of Care

- What went wrong? -

- Early start of epilepsy – “forgotten” patient
- No intensive search for aetiology (normal MRI –never questioned)
- No alternative treatment consideration (standard of care?)

- *Aetiology search inadequate – **specialized MRI in an epilepsy center***
- *MRI-standards inadequate – **not evaluated by experienced hands***
- *Possible danger for the patient – **SUDEP and reduced life perspectives like suicide x 5, drowning x 20, etc.***

Surgery for Temporal-Lobe Epilepsy



The Alternative

- Early Epilepsy Surgery -

Early surgical therapy for drug-resistant temporal lobe epilepsy:
a randomized trial

Engel et al., JAMA 2012

2 years – 2 „brand name“ AED - AMTE Continued AED-Therapy

2 years follow-up – 200 planned – **15/23** included

11/15 versus **0/23** became seizure free $p < 0.001$

Standard of Care

- The Problem -

- About 6 000 epilepsy patients per million population
- 1/3 are problematic to treat or untreatable (2 000)
- The density of neurologist in Europe is highly variable
- The knowledge of epilepsy by MDs is highly variable
- There is no systematic program (guidelines) in the escalation in diagnoses and treatment in Epilepsy for *Europe*.

Standard of Care

- A possible solution – *the Network* -

neurologist or paediatricians (MDs)

“epileptologists”

Research centers

Epilepsy centers

1 center per 2 -3 millions inhabitants
Responsibility for > 4 000 “difficult” patients

Standard of Care

- Epilepsy Center -

➤ ***All diagnostic procedures***

experienced and qualified MDs, long-term monitoring, qualified MRI (neuroradiology, PET), neuropsychology, service: psychiatry, social work

➤ ***All therapeutic procedures***

drug therapy, resective epilepsy surgery, stimulation procedures, ketogenic diet, etc,
***educational programs, study programs,
new therapies - controlling***

➤ ***Research***

Standard of Care

- The Concept -

GPs, neurologists, paediatricians

Education

Specialists

Epilepsy centers

Easy to treat?

Difficult to treat

Standard operation procedures (SOPs)

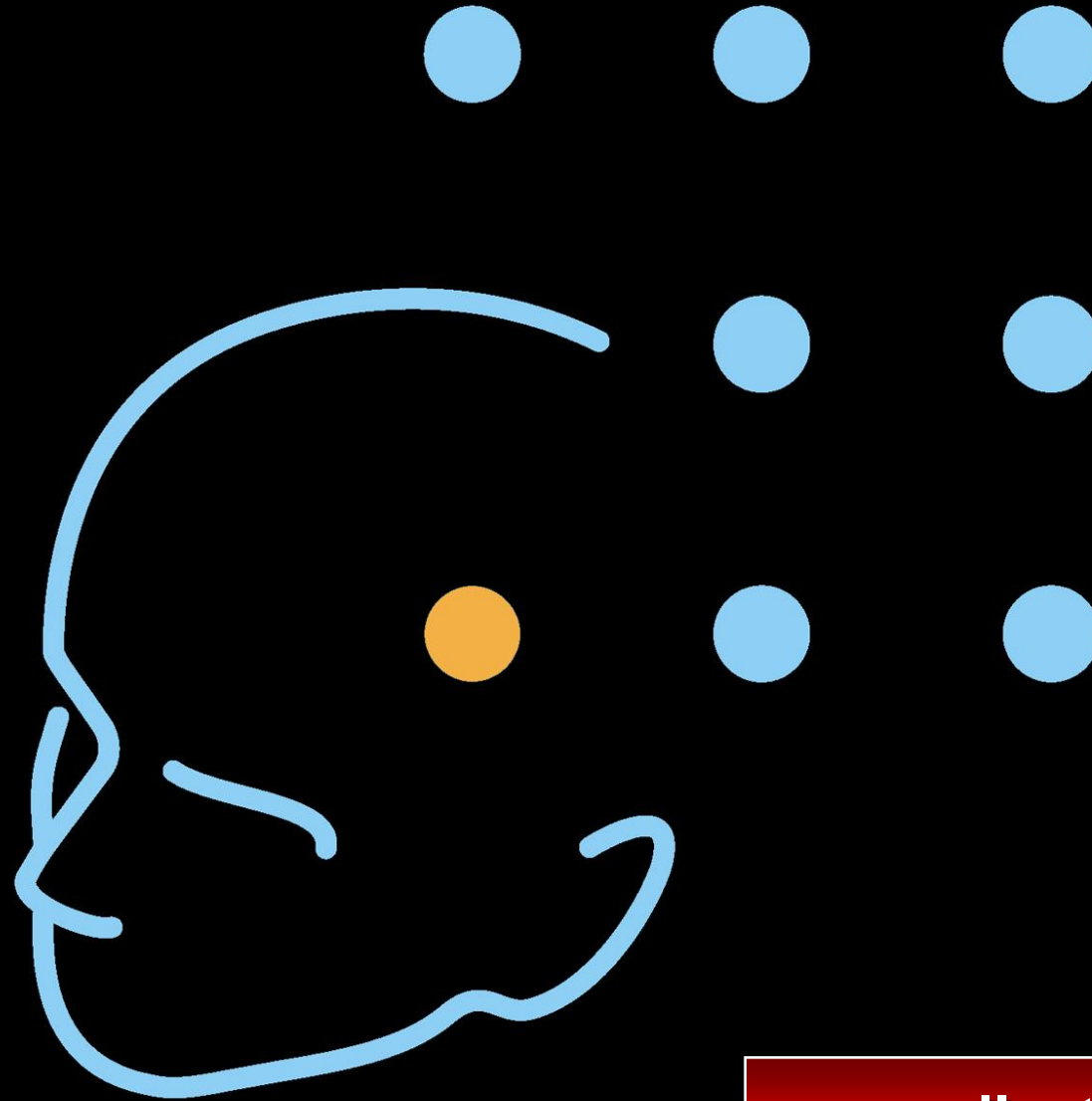
2 years

5 years

~~untreated~~

European Guidelines

How to deal with epilepsy patients
- a practical guide -



www.epileptologie-bonn.de