

**Provincial Comprehensive Epilepsy Care in Ontario:
A Novel Regionalized System of Care
and
Provincial Treatment Guidelines for Primary Care Providers**



**Critical Care Services Ontario
Epilepsy Implementation Task Force**

CCSO Critical Care Services Ontario

ONTARIO'S CRITICAL CARE SYSTEM TRANSFORMATION TIMELINE

SARS highlighted the need to improve Ontario's critical care system to better respond to sudden surges in demand.

2003

2004

MOHLTC began a formal review of adult critical care services in Ontario. A Steering Committee was established to study Access, Accountability, HR, Surge Capacity and New Technologies.

2005

Steering Committee report published with recommendations to improve the quality and efficiency of adult critical care services in Ontario.

2006

MOHLTC announced \$90 Million for a Critical Care Strategy. The Critical Care Secretariat was established.

2006-2012

The Critical Care Secretariat played an important role in developing the initiatives under Ontario's Critical Care Strategy.

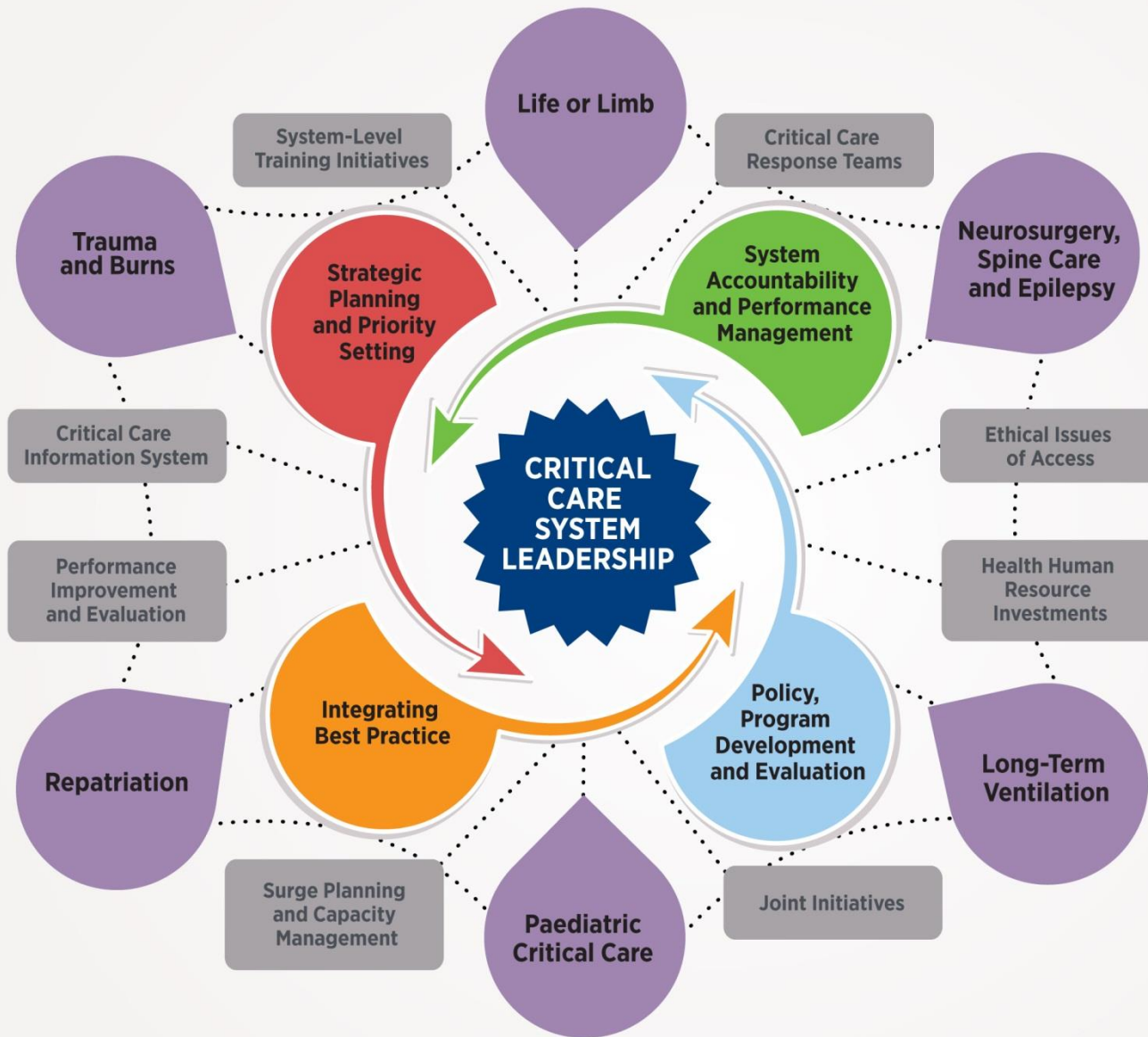
2012

Transformation to CCSO
The Secretariat expanded to incorporate programs such as Neurosurgery, Trauma and Burns, Paediatric critical care and Chronic Ventilation. The evolution of CCSO is supported by the Provincial Programs Branch at the Ministry.

2014

CCSO leading improvements and system innovation in critical care

CCSO Leading System Integration



- VALUES**
- Patient-focus
 - Collaboration
 - Leadership
 - Credibility
 - Results
 - Innovation
 - Knowledge Based Improvement
 - Transparency

Access Quality System Integration Value

Critical Care Services Ontario (CCSO)

Scope and Role:

- CCSO is responsible for leading the overall planning, implementation and evaluation of critical care services for the province of Ontario.
- CCSO works collaboratively with LHINs and healthcare providers to design and oversee a critical care system that meets the needs of critically ill patients across Ontario.
- CCSO has been assigned as a dedicated resource to support the implementation of Provincial neurosurgery initiatives.



Background: Provincial Neurosurgery Strategy

- In early 2011, the Ministry requested that Dr. Robert Bell and Dr. Jim Rutka lead a planning process focused on developing a comprehensive neurosurgical system that will meet the needs of adult and paediatric patients across Ontario.
- Their efforts resulted in a final report to MOHLTC (Dec. 2011) which outlined recommendations aimed at improving the access, quality and responsiveness of neurosurgical care.
- The Epilepsy Implementation Task Force (EITF) as a working group of PNO, was tasked to bring together key stakeholders to provide a provincial perspective in order to maximize value from the system of epilepsy care in Ontario. This includes:
 - ✓ Improving access along the full continuum of care by coordinating resources and wait lists
 - ✓ Establishing standardized diagnostic and surgical protocols across centres
 - ✓ Developing supports for primary care providers

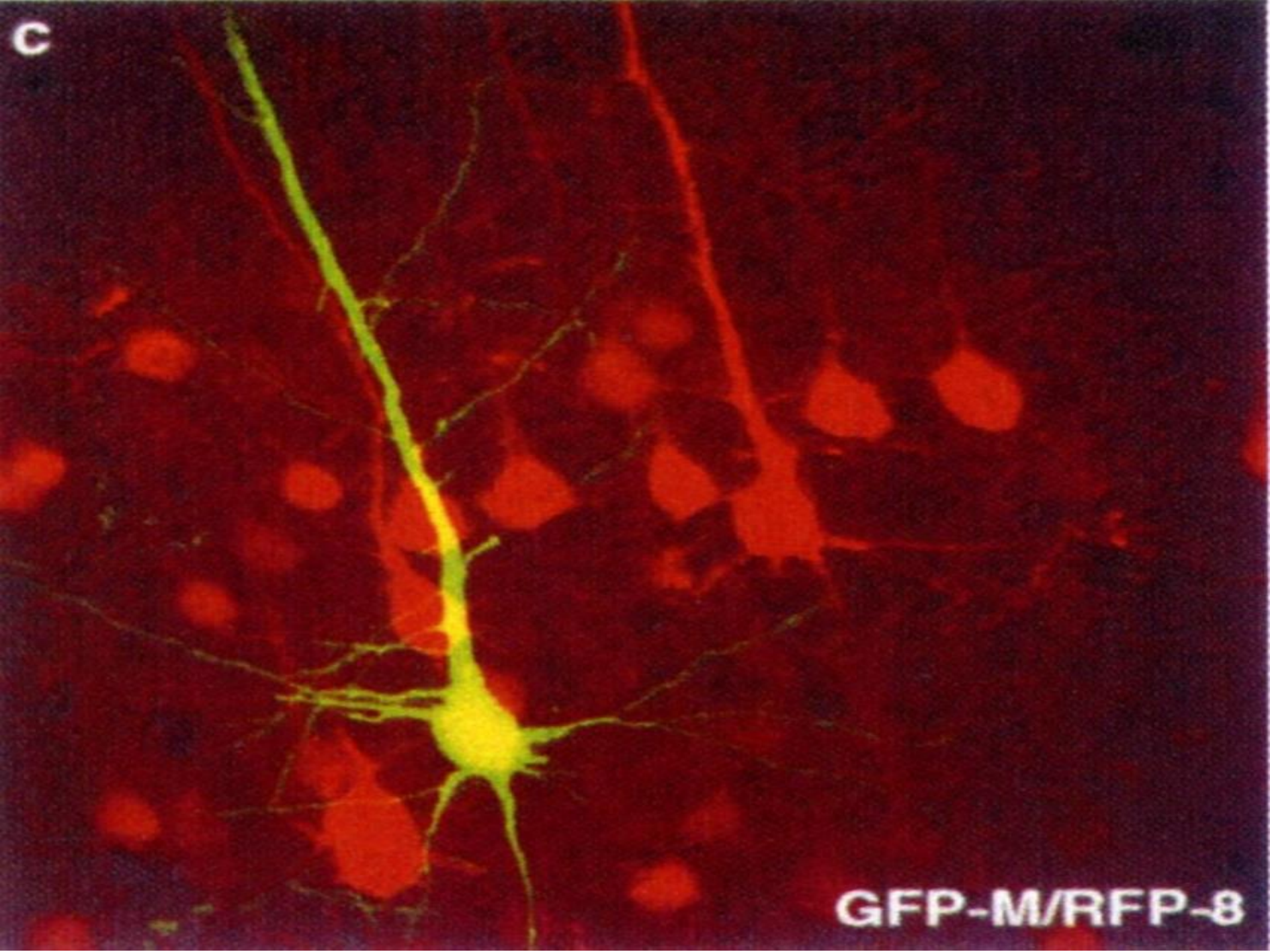


Epilepsy in Ontario

Dr. Carter Snead

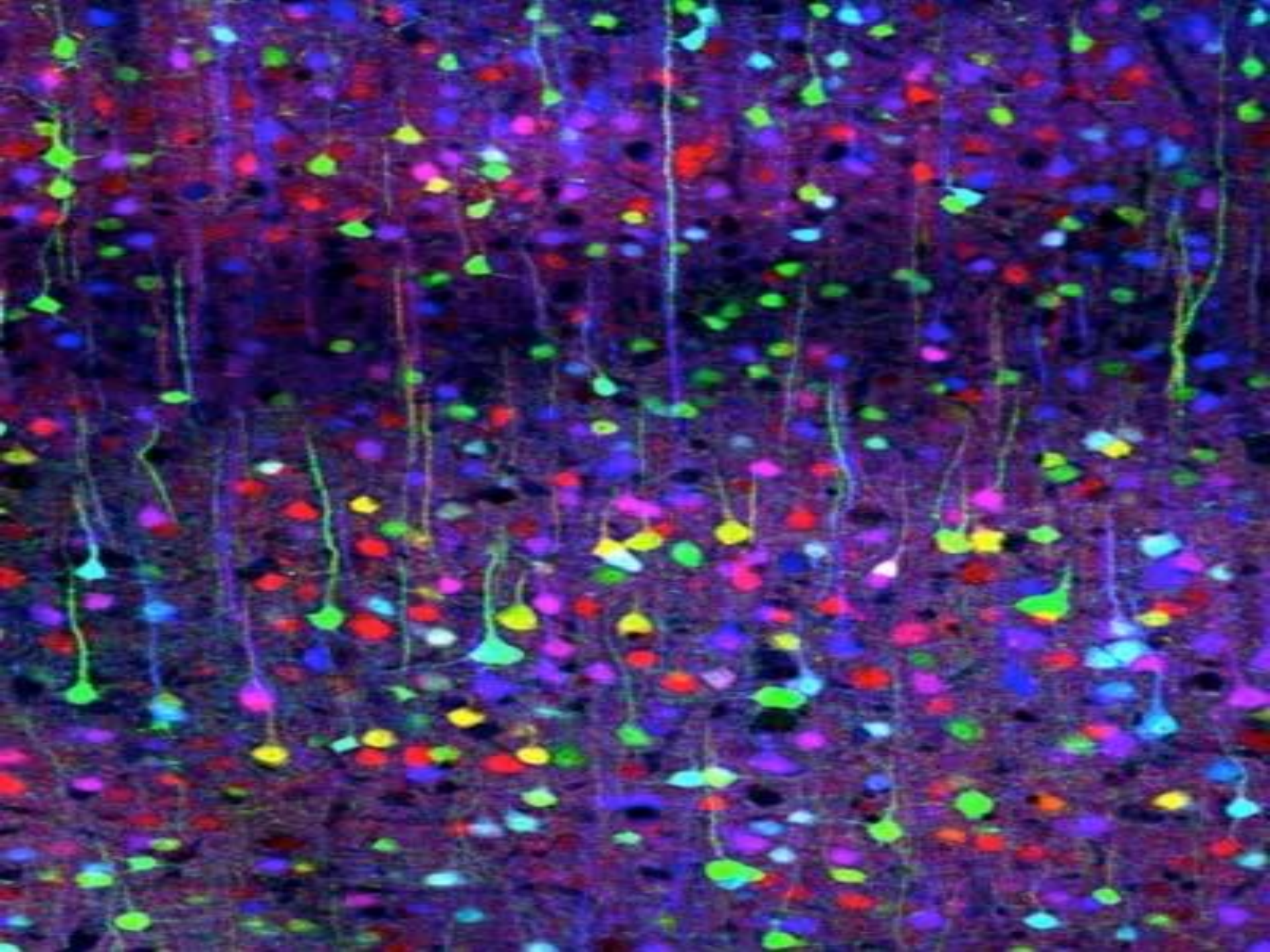


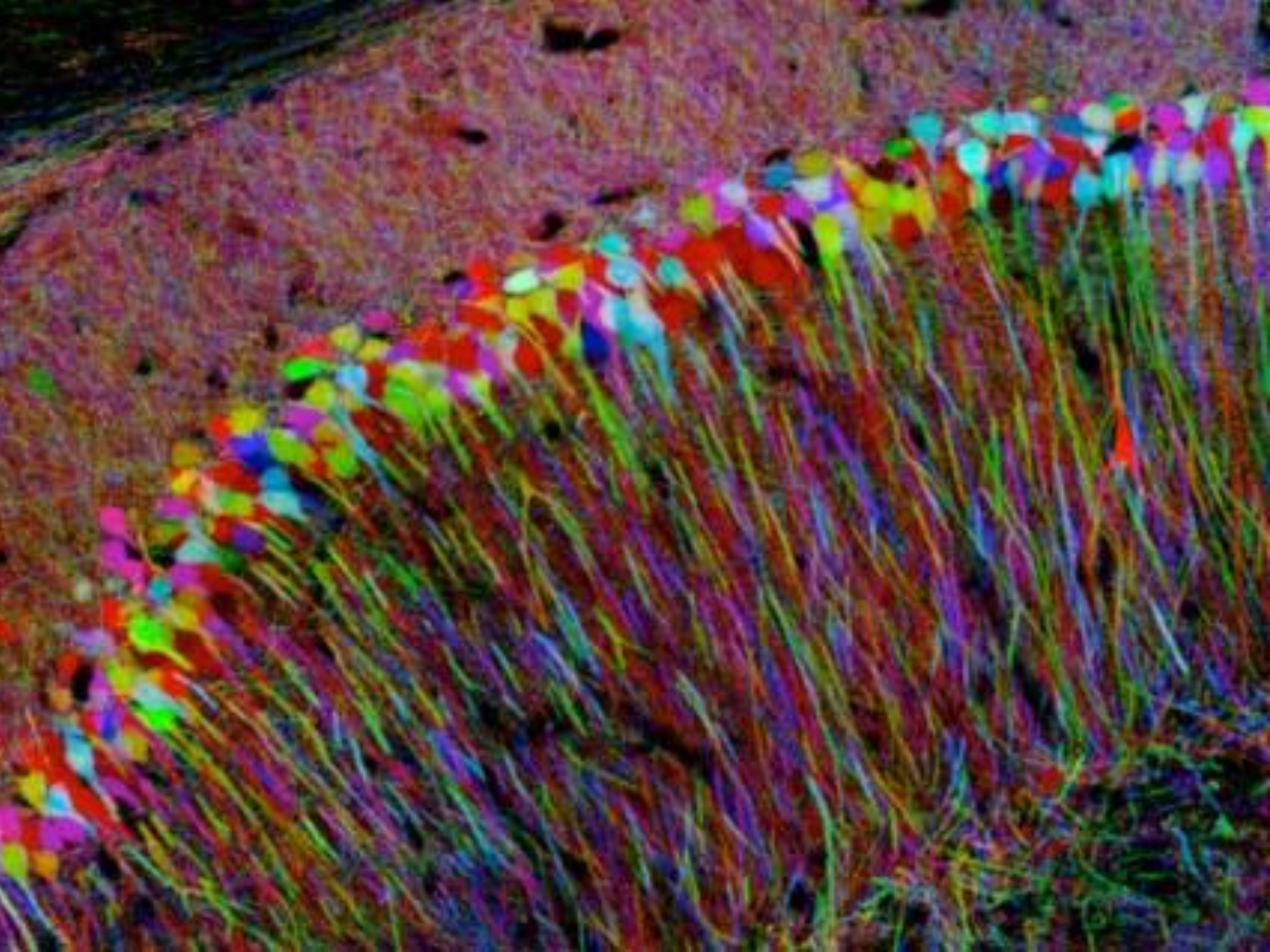
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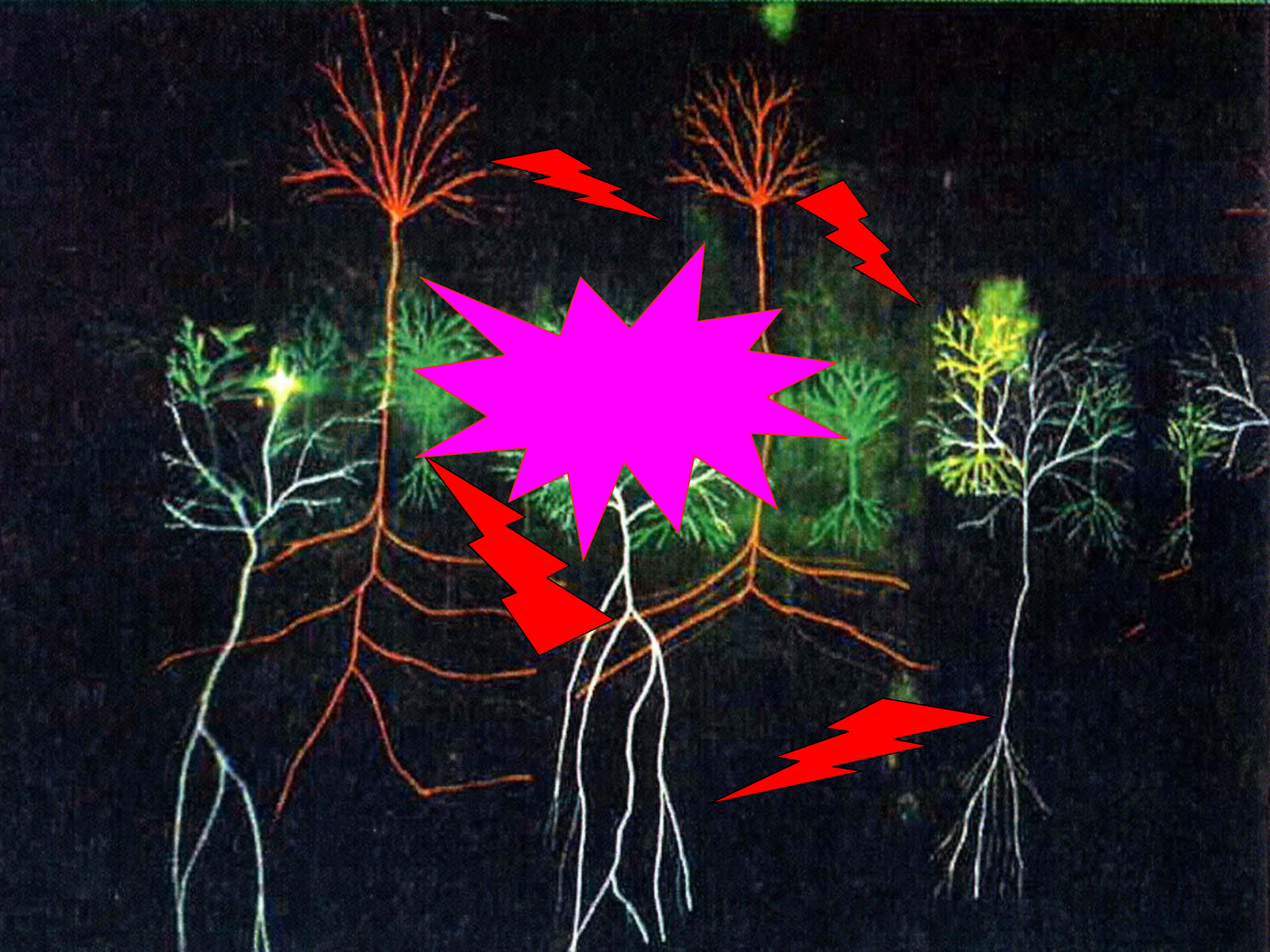
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Background: What is a Seizure?

Epileptic Seizure

- An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive and or synchronous neuronal activity in the brain (Fisher et al., 2005)



Background: What is Epilepsy?

Epilepsy

- Disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher et al, 2005). In most situations, occurrence of two epileptic seizures is an indication of enduring predisposition to generate epileptic seizures.



Background: Classification of Epileptic Seizures

1. Generalized seizures

- Conceptualize as originating at some point within, and rapidly engaging, bilaterally distributed networks. They can be classified as tonic-clonic, absence, myoclonic, clonic, tonic, and atonic.

2. Focal Seizures

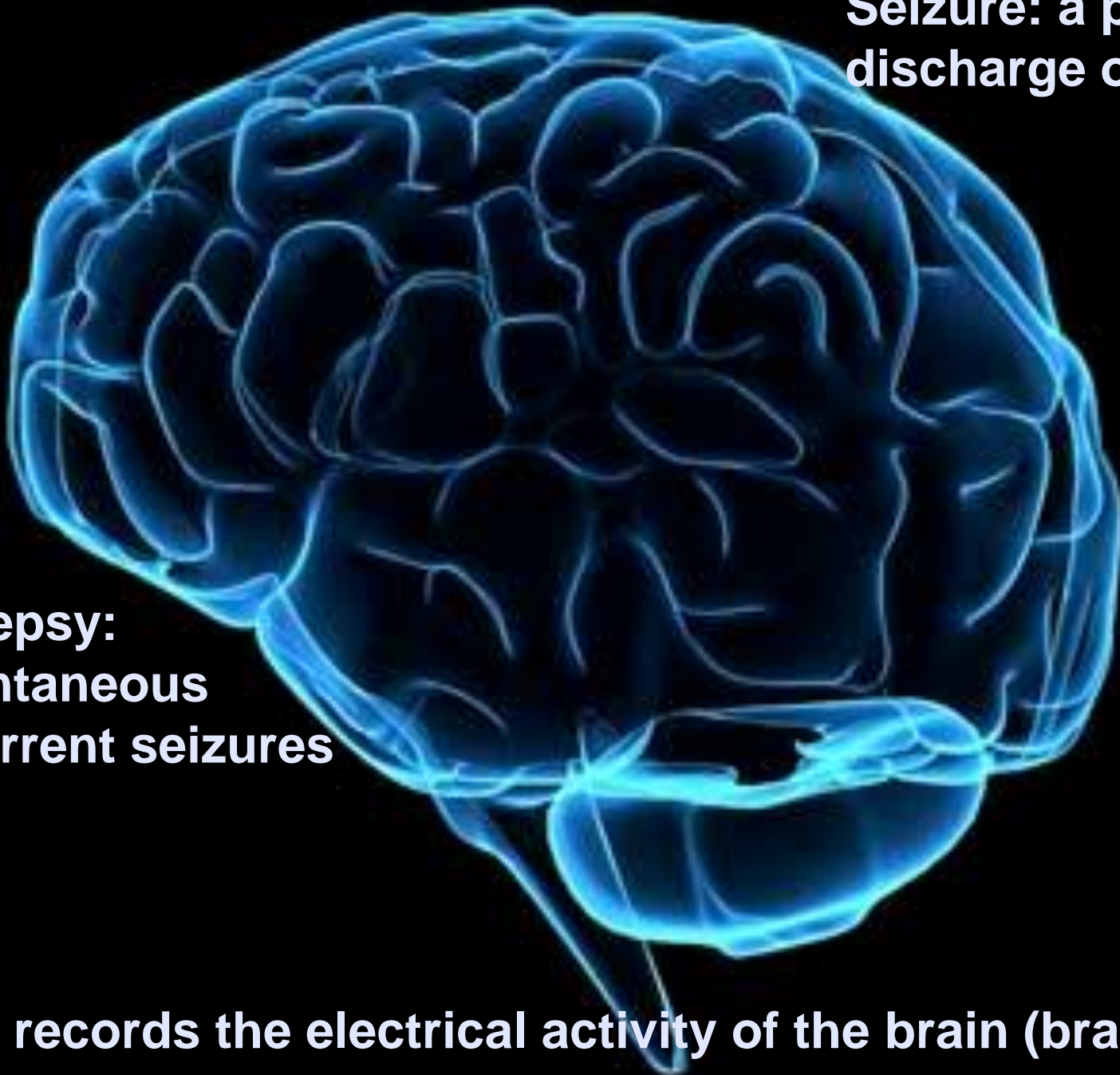
- Conceptualized as originating within networks limited to one hemisphere. Descriptors of focal seizures include:
 - Those without impairment of consciousness or awareness (concept of a simple partial seizure) but observable motor or autonomic components and/or subjective sensory or psychic phenomena (simple partial seizures)
 - Those with impairment of consciousness or awareness (concept of a complex partial seizure) - these may evolve to bilateral convulsive seizures

3. Unknown (i.e. epileptic spasms)

- Do not fit above criteria

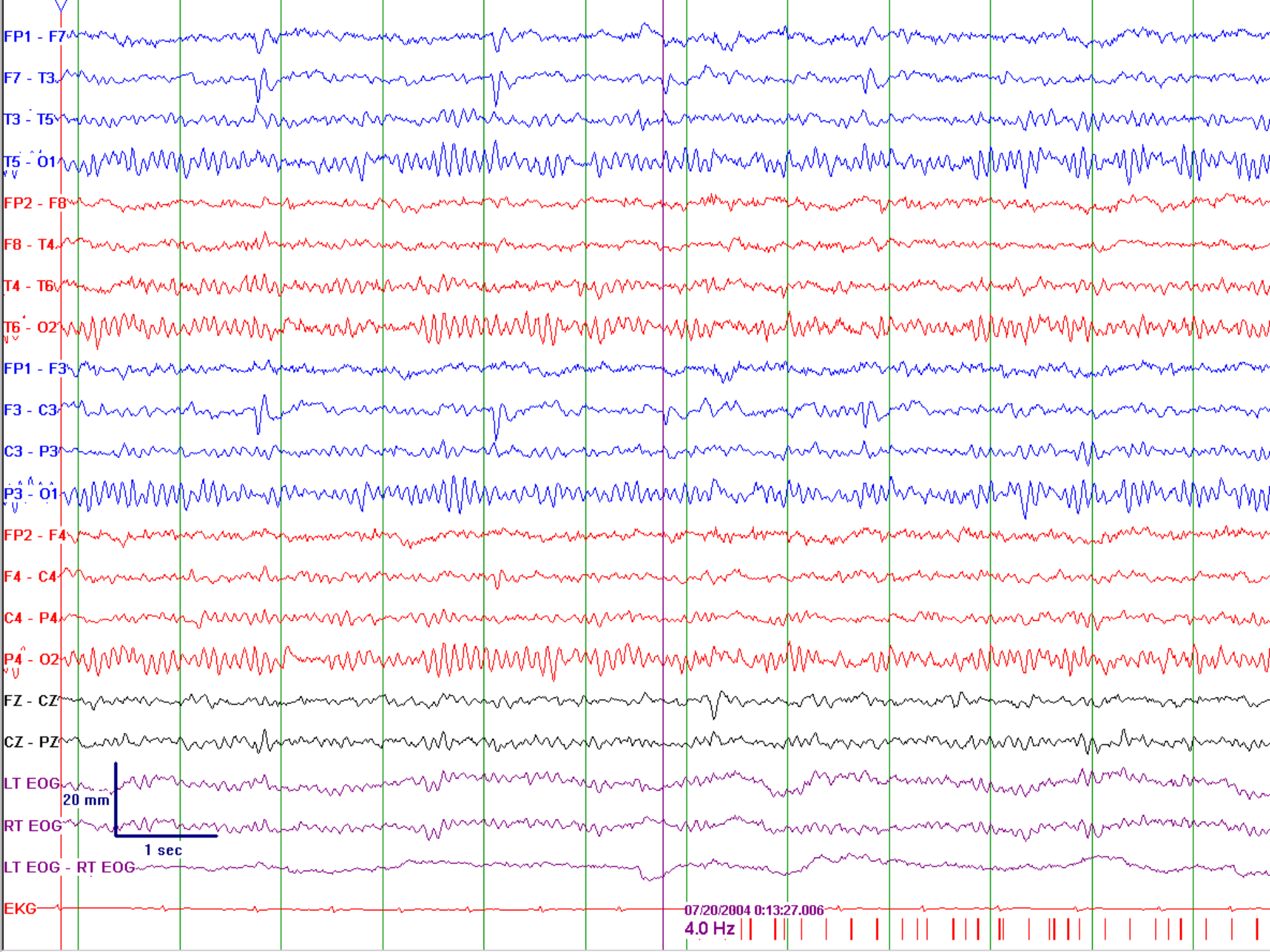


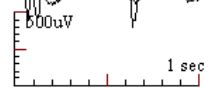
Seizure: a paroxysmal discharge of neurons



**Epilepsy:
spontaneous
recurrent seizures**

EEG records the electrical activity of the brain (brain waves)





Background: Epilepsy in Ontario

- 80,000 adults
- 15,000 children
- 30% of those diagnosed have medically-refractory epilepsy (seizures that do not respond to treatment with two or more appropriate antiepileptic drugs)
- Second only to headache as most common chronic neurological condition in Ontario
- There is approximately an 80% chance that an individual with medically-refractory epilepsy who is a surgical candidate will be seizure-free after surgery.
- Despite its apparent effectiveness, less than 2% of potential surgical candidates access surgical treatment.



Burden of epilepsy

People with epilepsy in particular those with poorly controlled seizures, tend to be burdened in the following ways:

- Social stigma
- Mental health and cognitive disability co-morbidity
- Poor school performance, peer relationships
- Higher unemployment
- Inability to drive
- Marriage and family less likely
- Lower educational status
- Higher mortality

.... **Unpredictability!!**



Background: Epilepsy in Ontario

- A 2012 OHTAC report by the Expert Panel on a Provincial Strategy for Epilepsy Care identified long wait lists at the province's Epilepsy Monitoring Units (EMUs) and low referral rates contributed to the underutilization of surgical treatment.
- Based on this report, the Ministry of Health and Long-Term Care (MOHLTC) made an investment of 21 new Epilepsy Monitoring Unit (EMU) beds in Ontario, bringing the total number of EMU beds to 39 (26 adult and 13 paediatric).
- The Epilepsy Implementation Task Force (EITF) was formed in June 2013 to develop and implement a provincial approach to an integrated system for epilepsy care in Ontario.
- The EITF has developed a definition of a Comprehensive Epilepsy Program (CEP)



Background: Epilepsy in Ontario

- A CEP is an integrated care model for the management of individuals with epilepsy within a multidisciplinary team. A CEP covers various aspects of care including medical, psychosocial, and nutritional management, appropriate neurodiagnostic investigations, a mandatory EMU, capability for presurgical diagnostic evaluation, and established links to Community Epilepsy Agencies.
- A District Epilepsy Centre (DEC) houses a comprehensive epilepsy program that provides all appropriate epilepsy related clinical services except epilepsy surgery. A DEC should provide basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an Epileptologist, and full EMU service including neuropsychological evaluations. The following hospitals are classified as District Epilepsy Centres:

Hospital	Adult Beds	Paediatric Beds
Health Sciences North (operational 2015)	1	-
Hamilton Health Sciences	3	2
The Ottawa Hospital	2	-
Children's Hospital of Eastern Ontario	-	2



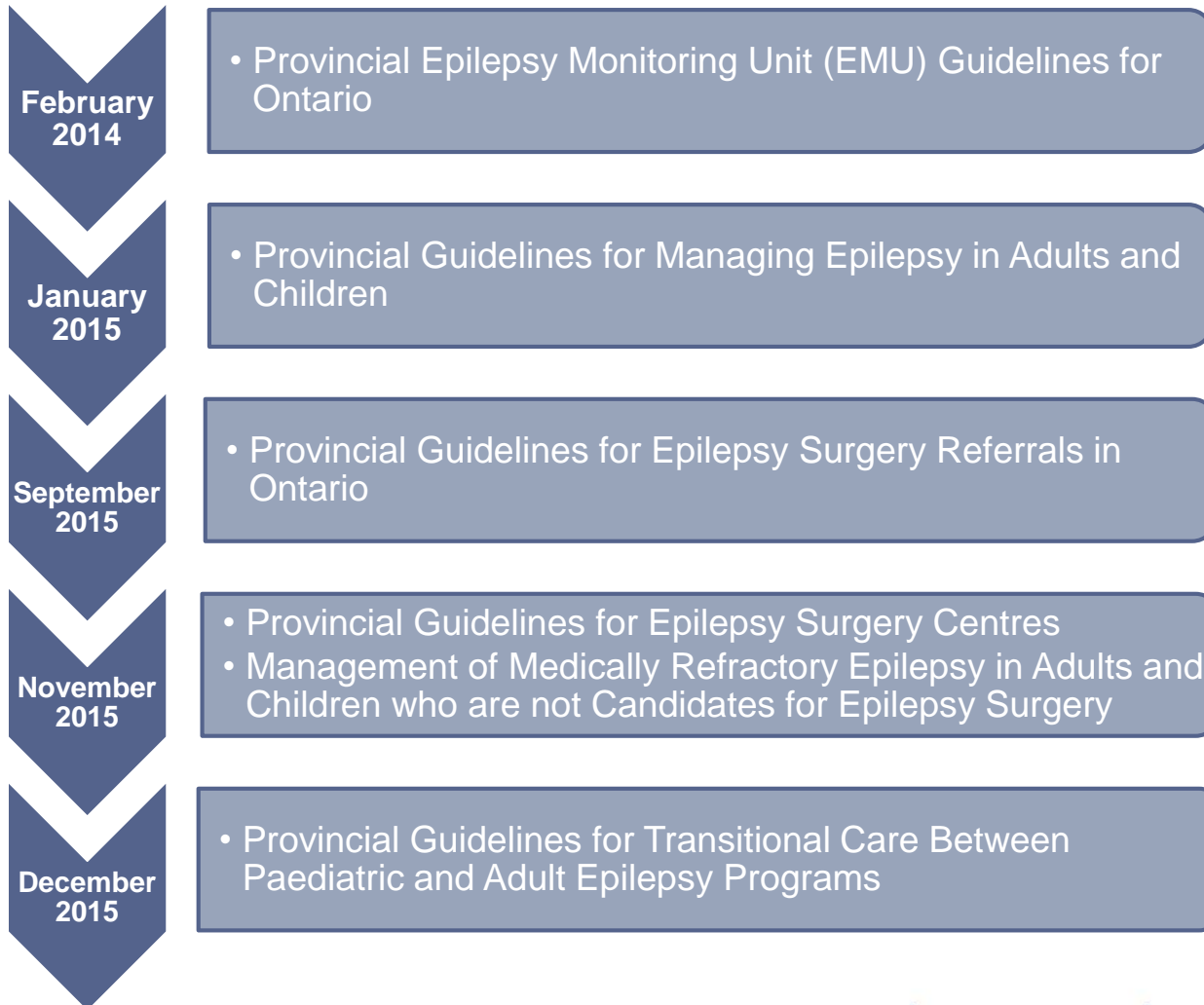
Background: Epilepsy in Ontario

- A Regional Epilepsy Surgery Centre (RESC) is a facility with a comprehensive epilepsy program that provides all the services available in a DEC, and in addition, epilepsy surgery including facility for intracranial monitoring. An RESC is also a DEC for its catchment area.
- The following hospitals are classified as Regional Epilepsy Surgery Centres:

Hospital	Adult Beds	Paediatric Beds
London Health Sciences Centre	10	2
Hospital for Sick Children (SickKids)	-	7
University Health Network (Toronto Western Hospital)	10	-



Epilepsy Guideline Series



Provincial Treatment Guidelines for Primary Care Providers

Maria Zak, MN, NP-Paediatrics



CCSO Critical Care Services Ontario

Epilepsy Snapshot: Guideline Highlights

Diagnosis:

- Description of the event/seizure
- Associated symptoms
- Ancillary information
- Neurologic examination
- EEG, MRI of brain

Treatment:

- Antiepileptic drug (AED)
- Surgery

Patient/Caregiver Education:

- Lifestyle and psychosocial implications
- Seizure types, syndromes and treatment options

Women with Epilepsy:

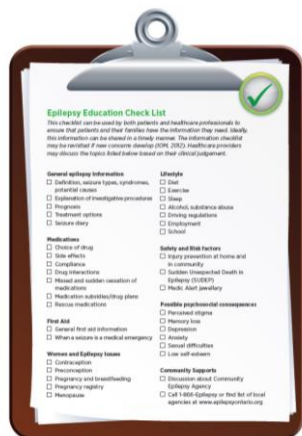
- Pregnancy, contraception, menopause

Patient Referrals:

- All patients who fail to respond to the first AED should be referred to a specialist
- All patients with medically-refractory epilepsy should be referred to an epileptologist at a District Epilepsy Centre to assess surgical candidacy

Follow Up:

- Seizure types, efficacy and side effects for AEDs
- Follow up recommendations:
 - Age 1-12 years, every 3-6 months
 - Age 13 and up every 6-12 months



Jack

- Jack is a 3 year old healthy boy. His mother heard a thump from his room and went upstairs to investigate. She found Jack in his room lying on the floor with his limbs shaking. He was not conscious and was drooling. Jack had a fever earlier in the day but was otherwise well. She called 911.



Clinical Diagnosis of Epileptic Seizures

Outline for Seizure Assessment:

Associated factors

- Age
- Family history
- Developmental status
- Behavior
- Health at seizure onset
- Precipitating events other than illness—trauma, toxins



Clinical Diagnosis of Epileptic Seizures

Outline for Seizure Assessment:

First Nonfebrile Seizure

- Health at seizure onset—febrile, ill, exposed to illness, complaints of not feeling well, sleep deprived
- Symptoms during seizure (ictal)
- Aura: Subjective sensations
- Behavior: Mood or behavioral changes before the seizure
- Preictal symptoms: Described by patient or witnessed
- Vocal: Cry or gasp, slurring of words, garbled speech
- Motor: Head or eye turning, eye deviation, posturing, jerking (rhythmic), stiffening, automatisms (purposeless repetitive movements such as picking at clothing, lip smacking); generalized or focal movements
- Respiration: Change in breathing pattern, cessation of breathing, cyanosis
- Autonomic: Pupillary dilatation, drooling, change in respiratory or heart rate, incontinence, pallor, vomiting
- Loss of consciousness or inability to understand or speak
- Duration of seizure



Clinical Diagnosis of Epileptic Seizures

Outline for Seizure Assessment:

Symptoms following seizure (postictal)

- Amnesia for events
- Confusion
- Lethargy
- Sleepiness
- Headaches and muscle aches
- Transient focal weakness (Todd's paresis)
- Nausea or vomiting



Treatment

General Principles of AED Treatment: Monotherapy

- It is recommended that children, young people and adults should be treated with a single AED (monotherapy) whenever possible.
- If the initial treatment is unsuccessful, then monotherapy using another drug or add-on treatment with a second drug can be tried. Caution is needed during the changeover period. If an AED has failed because of adverse effects or continued seizures, a second drug should be started (which may be an alternative first-line or second-line drug) and built up to an adequate or maximum tolerated dose and then the first drug may be tapered off slowly.
- If the second drug is unhelpful, either the first or second drug may be tapered, depending on relative efficacy, side effects and how well the drugs are tolerated before starting another drug. Some patients are required to be on more than 2 AEDs.



Treatment

General Principles of AED Treatment: Adjunctive Therapy

- It is recommended that combination therapy (adjunctive or 'add-on' therapy) should only be considered when attempts at monotherapy with the tolerated dose of AED have not resulted in seizure freedom. If trials of combination therapy do not bring about worthwhile benefits, treatment should revert to the regimen (monotherapy or combination therapy) that has proved most acceptable to the child, young person or adult, in terms of providing the best balance between effectiveness in reducing seizure frequency and tolerability of side effects.
- AED interactions and comorbidities should be taken into consideration when choosing combination therapy.
- If there is no improvement after two adequate trials of AEDs, the patient should be referred for epilepsy surgery evaluation.



Follow Up

In the first year of life, infants should be seen every 3 months for assessment of their growth and development for the following reasons:

- To assess the neurodevelopmental progress
- To adjust their medication dose for growth, if required

Age 1 year to 12 years, toddlers and children should be reviewed every 3-6 months for the following reasons:

- To assess the developmental progress
- To discuss the school performance
- To discuss risks of seizures while engaged in water sports, bathing etc.

Age 13-17 teens can be reviewed every 6-12 months:

- To readjust medication need at the onset of puberty, if required
- To discuss the effect of alcohol on epilepsy threshold
- To discuss pregnancy planning need in teenage girls with epilepsy
- To discuss driving laws as applicable to epilepsy
- To discuss transition to adult care

Adults with epilepsy can be reviewed every 3-6 months:

- To adjust medication for side effects/ poor seizure control
- To assess social adjustment and offer counseling in patients experiencing difficulty/discrimination
- To review seizure control during pregnancy



Follow Up: Patient Education

General Epilepsy Information	Medications	First Aid	Women and Epilepsy Issues	Lifestyle	Safety and Risk Factors	Possible Psychosocial Consequences
<ul style="list-style-type: none"> • Definition, seizure types, syndromes, potential causes • Explanation of investigative procedures • Prognosis • Treatment options • Seizure diary 	<ul style="list-style-type: none"> • Choice of drug • Side effects • Compliance • Drug interactions • Missed and sudden cessation of medications • Medication subsidies/drug plans • Rescue medications 	<ul style="list-style-type: none"> • General first aid information • When a seizure is a medical emergency 	<ul style="list-style-type: none"> • Contraception • Preconception • Pregnancy and breastfeeding • Pregnancy registry • Menopause 	<ul style="list-style-type: none"> • Diet • Exercise • Sleep • Alcohol, substance abuse • Driving regulations • Employment • School 	<ul style="list-style-type: none"> • Injury prevention at home and in community • Sudden Unexpected Death in Epilepsy (SUDEP) • Medical alert jewelry 	<ul style="list-style-type: none"> • Perceived stigma • Memory loss • Depression • Anxiety • Sexual difficulties • Low self-esteem

Community Supports-Community Epilepsy Agency

Call 1-866-Epilepsy or find list of local agencies at www.epilepsyontario.org



Co-Morbidities

The following are co-morbid conditions with significantly higher rates in patients with epilepsy than the general population:

Medical

- Musculoskeletal system disorders
- Gastrointestinal and digestive disorders
- Respiratory system disorders
- Chronic pain disorders
- Cerebrovascular accidents
- Migraine
- Neoplasia
- Arthritis/rheumatism

Medical (Continued)

- Obesity
- Diabetes
- Infections
- Fractures
- Allergies
- Alcoholism
- Drug abuse

Psychiatric

- Depression
- Anxiety
- Autism spectrum disorders
- Interictal dysphoric disorder
- Interictal behavior syndrome
- Psychosis of epilepsy

Cognitive

- Attention-deficit hyperactivity disorder
- Learning disability
- Intellectual Development Disorder
- Alzheimer's disease/dementia



Psychosocial/Mental Health

Anxiety:

- The prevalence of various forms of anxiety is very high among persons with epilepsy, ranging from 19-60% (Jones et al., 2005).
- Panic disorder, generalized anxiety disorder, phobias and obsessive compulsive disorders are all increased in persons with epilepsy (Beyenburg et al., 2005)
- Patients with epilepsy should be screened for symptoms of anxiety
- Patients should be referred to neuropsychiatry/psychiatry or a clinical psychologist, as appropriate

Depression:

- Depression is increased in people with epilepsy, with a lifetime prevalence of about 30% (Tellez-Zenteno, Patten, Jette, Williams, & Wiebe, 2007).
- Screening for depression using the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E), Patient Health Questionnaire (PHQ-2), or equivalent tool should ideally be undertaken for all patients (adults and adolescents aged 13-17 years) with epilepsy.



More Information

The complete Provincial Guideline for the Management of Epilepsy in Adults and Children can be found at www.criticalcareontario.ca under tools/library.

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Discussion / Questions?
THANK YOU!