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Break Down the Barriers
And
Stand Up for Epilepsy

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Ελληνική Εθνική Ένωση κατά της Επιληψίας
Greek Association against Epilepsy

*“Knowing is not enough; **we must Apply**.*
*Willing is not enough; **we must Do**.”*
Goethe

Literature Review

Begley et al., (2000) estimated that the total annual **cost of epilepsy** in the United States was
$12.5 billion per year,

- $10.8 billion *in indirect costs* (86.5%) &
- $1.7 billion in direct costs (13.5%)

Biomedical perspective devotes most of attention in seizure control/management care.

Biopsychosocial perspective focuses on the effect of epilepsy on the *whole person*.

Quality of Life

World Health Organization (1996; p.5).

“Quality of life is defined as individuals’ perceptions of their position in life in the *context of the culture* and *value systems* in which they live and in relation to their goals, expectations, standards and concerns”.

PARADOX?

People with epilepsy (PWE):
90% of self-ratings regarding Health Related QoL was explained by a combination of

- Disease severity,
- Epilepsy self-efficacy,
- Social support & Locus of control.

As social support increases, the sense of mastery increases, and hence, the person's ability to cope with the limitations of their disease improves.

Amir, Roziner, Knoll, Neufeld, (1999)

Social support

Supportive resources aim to enhance an individual's QoL by guaranteeing that the person is part of a broader social network and receives extended input that will help him cope with *the reality of his condition.*

- Emotional (e.g., nurturance)
- Tangible (e.g., financial assistance)
- Informational (e.g., advice) or companionship (e.g., sense of belonging)
- Intangible (e.g. personal advice)

Epilepsy's Social Support Network

HEALTH Care providers

**FAMILY,
FRIENDS,
PARTNER**

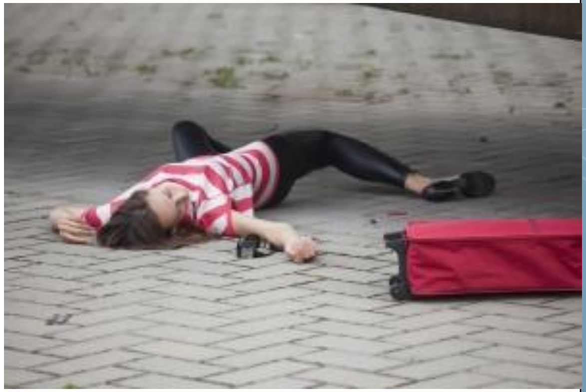
International Organizations
(AES, ILAE, Epilepsy Foundation, & ETP)

Community Organizations

Reality Checks for PWE

PWE are prevented from living a completely self-reliant life depending on:

- Seizure frequency,
- Age at time of onset,
- Adherence to medication
- Cognitive abnormalities/deficiencies
- Chronicity of the disease
- Family psychopathology
- Social stigma



SOCIAL RELATIONS

Psychosocial problems as they relate to a patient's adaptation to epilepsy

- Unpredictability of seizure/severity/place
- Discrimination or rejection may hinder socializing
- Family & friends overprotectiveness
- Physicians failure to recognise and promote patient autonomy
- Dating, sexuality & marriage seen as difficult to attain
- Driving inability is a barrier
- Unemployment

Livneh,Wilson, Duchesneau, Antonak, (2001)

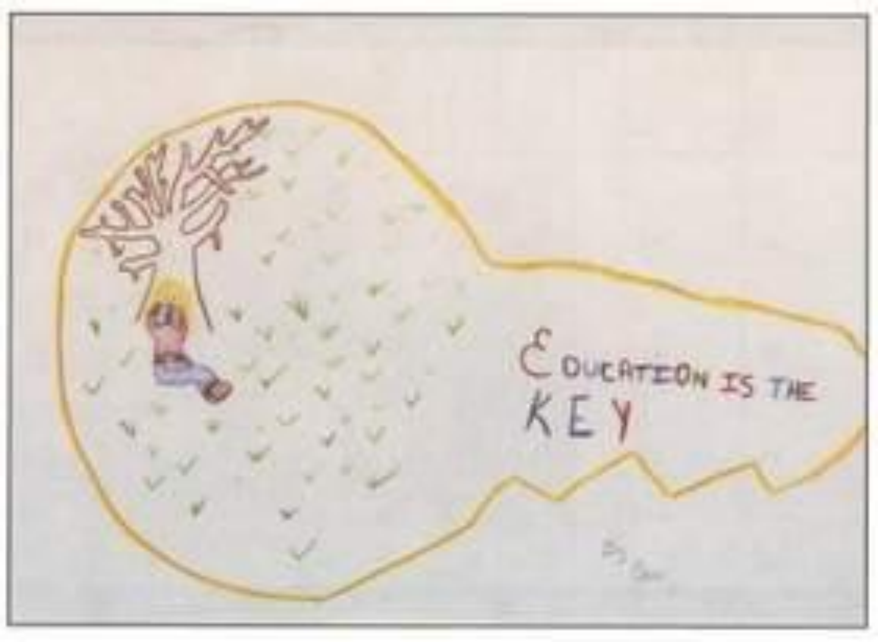
Trapped by epilepsy…

www.dystoniasufferer.com

What is the Role of Epilepsy Support Groups?

- In-person support groups
- Online forums
- Epilepsy Connection
- Group Support

HOW?



EDUCATION is the KEY

Education efforts for people with epilepsy and their families need to be thorough and sensitive to

- **health literacy** and
- **cultural considerations**.

What is the Role of Epilepsy Support Groups?

EPILEPSY
FOUNDATION®

Practice *in skills* on how to socialize

Encouragement from meeting others who have faced similar challenges & have coped with

Acceptance by a group of people who share your feelings & experiences

Comfort from seeing that you are not alone

Empowerment through increased ***knowledge & confidence***

http://www.epilepsy.com/epilepsy/support_groups

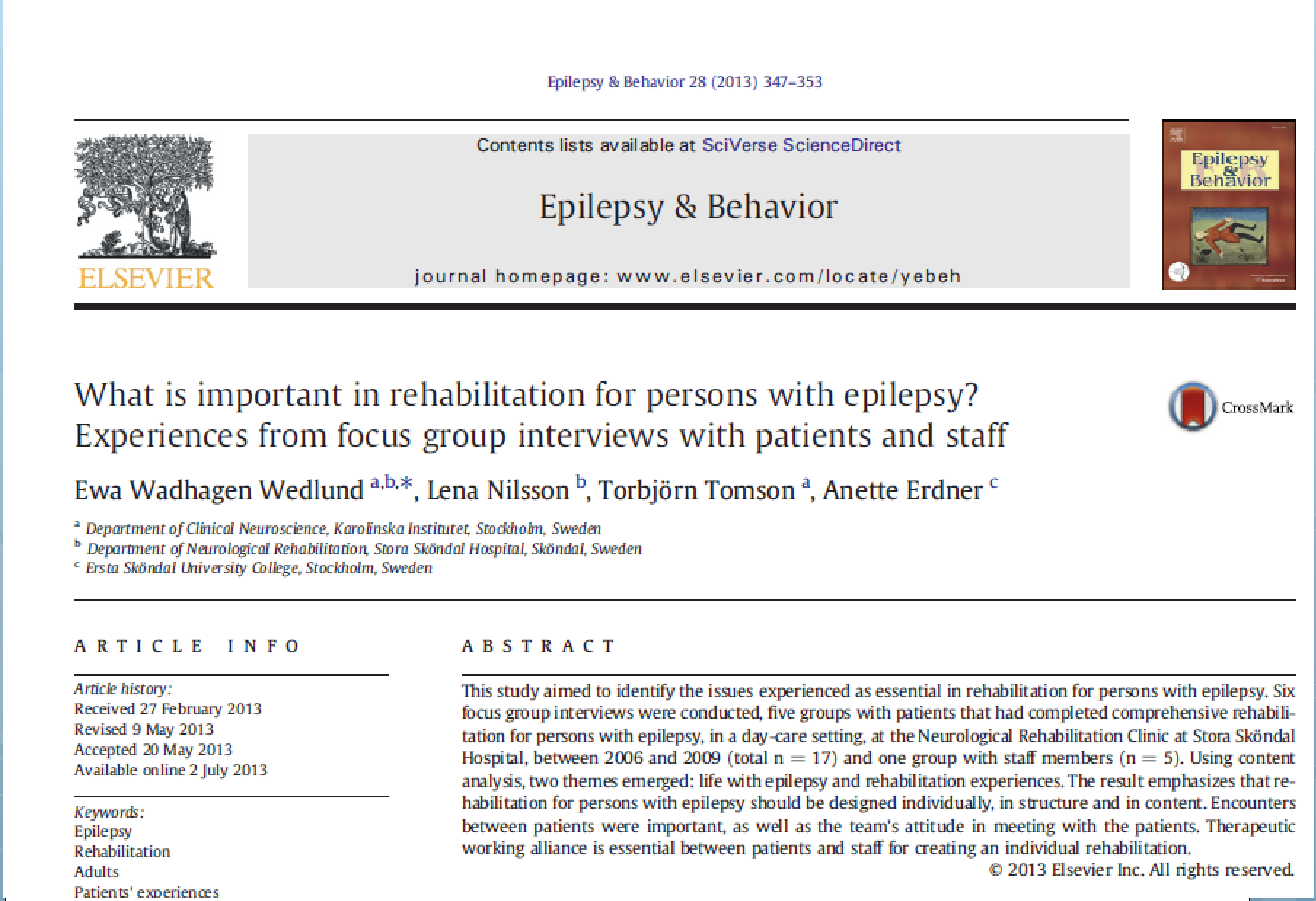
FOCUS

Patient-centered approach:

- ❑ Educational programs should involve the patient as an **active participant** in treatment to meet his needs.
- ❑ Day-to-day **self- management** skills teaches wellness skills and enhances patient's **self-efficacy**.
- ❑ Being locally focused, takes into account the full **range of resources** in the area.

Mahrer-Imhof, Jaggi, Bonomo, Hediger, Eggenschwiler, Kramer, & Oberholzer (2012)

Epilepsy Rehab



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What is important in rehabilitation for persons with epilepsy? Experiences from focus group interviews with patients and staff

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ABSTRACT

This study aimed to identify the issues experienced as essential in rehabilitation for persons with epilepsy. Six focus group interviews were conducted, five groups with patients that had completed comprehensive rehabilitation for persons with epilepsy, in a day-care setting, at the Neurological Rehabilitation Clinic at Stora Sköndal Hospital, between 2006 and 2009 (total n = 17) and one group with staff members (n = 5). Using content analysis, two themes emerged: life with epilepsy and rehabilitation experiences. The result emphasizes that rehabilitation for persons with epilepsy should be designed individually, in structure and in content. Encounters between patients were important, as well as the team's attitude in meeting with the patients. Therapeutic working alliance is essential between patients and staff for creating an individual rehabilitation.

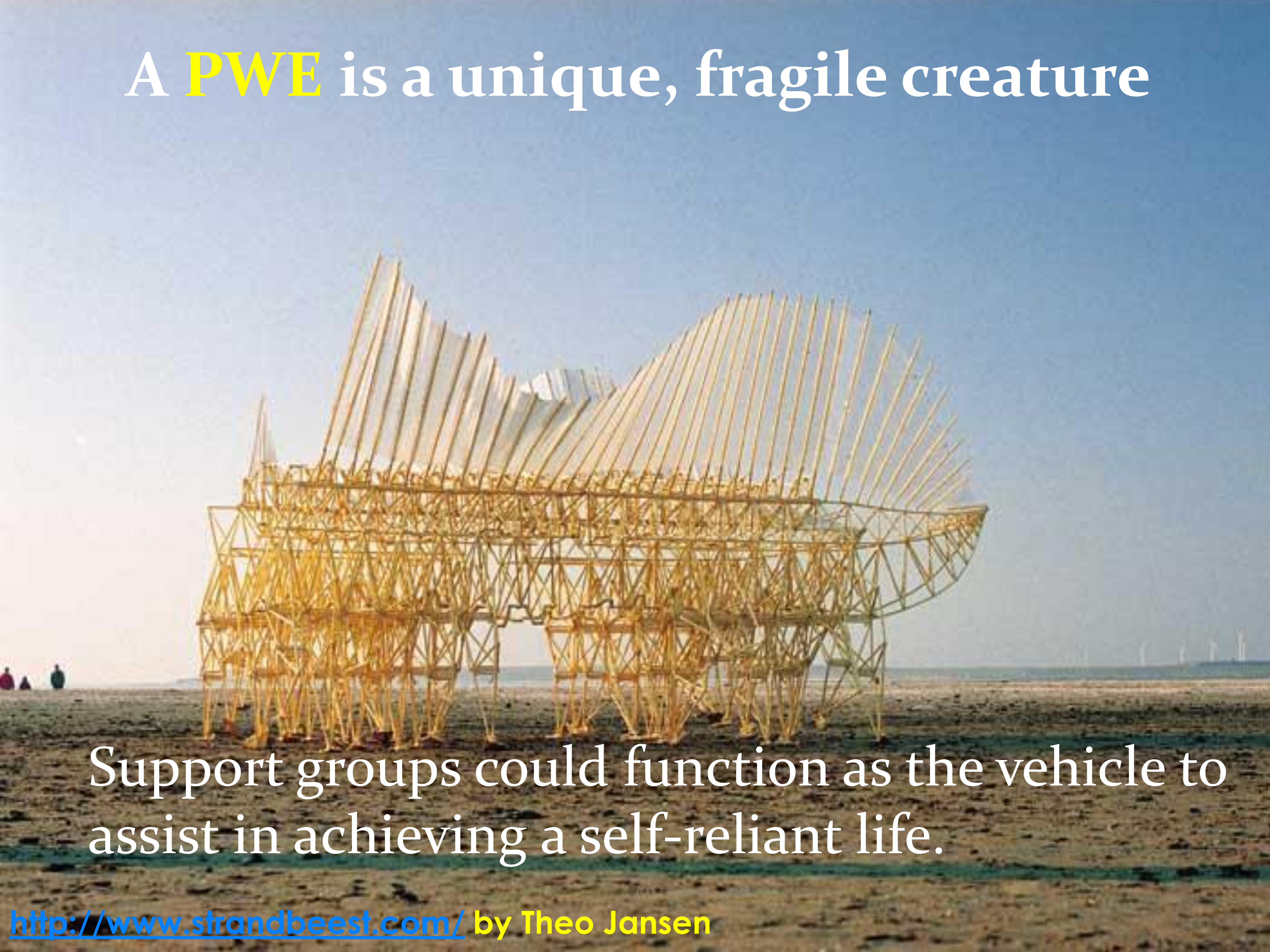
In summary

Community Services and Support Programs for Epilepsy Rehabilitation

✓Structured environment
✓Cognitive rehabilitation management
✓Psychological support

✓Staff continuous education plan

A PWE is a unique, fragile creature



Support groups could function as the vehicle to assist in achieving a self-reliant life.

http://www.strandbeest.com/ by Theo Jansen

REFERENCES

Jacoby A, Baker GA, Steen N, Potts P, Chadwick DW. (1996). The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. Community study. Epilepsia, vol. 37(2):148–61.

Livneh H,Wilson LM, Duchesneau A, Antonak RF (2001). Psychosocial adaptation to epilepsy: the role of coping strategies. Epilepsy Behav;2(6):533–44.

Mahrer-Imhof, Jaggi, Bonomo, Hediger, Eggenschwiler, Kramer, & Oberholzer (2012). Quality of life in adult patients with epilepsy and their family members. *Seizure, vol. 22, pp.128-135*.

REFERENCES

W.H. Theodore, S.S. Spencer, S. Wiebe, et al. (2006). Epilepsy in North America: a report prepared under the auspices of the Global Campaign Against Epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. Epilepsia; 47:1700–22.

Epilepsy across the spectrum : promoting health and understanding (2012). Mary Jane England, Catharyn T. Liverman, Andrea M. Schultz, and Larisa M. Strawbridge, *Editors.* Committee on the Public Health Dimensions of the Epilepsies, Board on Health Sciences Policy, Institute of Medicine of the National Academies.