

UEFA



we care

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY



**UEFA European
Under-21 Championship
Final Tournament**

International League
against Epilepsy (ILAE)
showcase matches

26 June 2009

PRESS BOOK



**International League against Epilepsy (ILAE)
showcase matches
26 June 2009**

FOREWORD



As European football has become a massively popular social activity, UEFA recognises the need to strengthen the positive role football plays in society by addressing themes that influence, and are influenced by, the sport. For that purpose, UEFA has established a Corporate Social Responsibility Unit that works with a wide range of external partners, using their expertise to promote respect for the game, respect for diversity and respect for the environment.

To raise public awareness of epilepsy and its implications, UEFA and the ILAE are co-organising a football showcase event in conjunction with the European Under-21 Championship in Sweden, with the active participation of the International Epilepsy Bureau (IBE). The event will consist of two short football matches played by teams of athletes with epilepsy from all over Europe, just before the European Championship semi-finals kick off on 26 June 2009. The teams will also include some top-level former professional footballers, who generously agreed to come to Gothenburg and Helsingborg to support our cause.

We hope this initiative will contribute to improving knowledge about epilepsy and, most importantly, emphasise that people with epilepsy are entitled and able to live a life that meets their expectations and to engage fully in social and professional activities.

We hope you all enjoy the event!

Michel Platini
President, UEFA

Alexis Arzimanoglou, Michel Baulac, Emilio Perucca, Solomon Moshé
ILAE Organizing Committee

**UEFA European Under-21 Championship
Final Tournament**

International League against Epilepsy (ILAE)

showcase matches

26 June 2009



The International League Against Epilepsy (ILAE) and the UEFA (European Football Association) are pleased to present you the football event they proudly co-organize, with the active participation of the International Bureau for Epilepsy (IBE).

The event will consist of two short football matches played by teams made up mostly of players with epilepsy from European countries. The main purpose is to emphasize that persons with epilepsy are entitled and able to live a normal life and to engage fully in social and sports activities and to perform just as well as people without epilepsy.



The event will take place in Sweden on Friday June 26th, 2009 just before the opening of the two semi-final games of the UEFA Under-21 championship and will consist of two matches between 4 teams (7 players per team, two half of 7 minutes each per match), with one match being played in **Göteborg** and the other in **Helsingborg**.



About Seizures and Epilepsies

Can people with epilepsy excel in sports?



The term **epilepsy** is loosely applied to a number of conditions that have in common only the propensity to the occurrence of sudden, transitory events known as **epileptic seizures**. The words **to seize** have an objective justification in the case of epilepsy because the attacks occur suddenly, frightening the patient, who has limited means to avoid the seizure or, in some cases, to protect himself from injury. The sudden, unexpected nature of epileptic attacks explains both the ancient magic concept that a seizure is caused by demonic possession and the more logical fear of the consequences of an event that is both unpredictable and repeated.

Epileptic seizures as an expression of a dysfunction in a brain region



Seizures can vary from the briefest lapses of attention or muscle jerks, to severe and prolonged convulsions (i.e. violent and involuntary contractions, or a series of contractions, of the muscles). Seizures can also vary in frequency, from less than one per year to several per day. These attacks result from the abnormal, excessive activity of groups of nervous cells in the brain. The characteristics of seizures vary and depend on where in the brain the disturbance first starts, and how far it spreads. Symptoms may be loss of awareness or consciousness, and/or disturbances of movement, sensation (including vision, hearing and taste), or mood. In other words, the conception that a seizure is always characterized by a wild agitation of the whole body is not correct. A simple repetitive jerking of an arm or repeated episodes of “rupture” of consciousness can be the only expression of an epileptic seizure.



A person, at any age, can have a single epileptic seizure. This occasional event - that may be due to fever, sleep deprivation, alcohol abuse and a variety of other causes - does not automatically mean that the person experiencing it has epilepsy. Up to 10% of people worldwide have one seizure during their lifetime. To be diagnosed as having epilepsy, the person has to present repeated seizure attacks.

Epilepsy or Epilepsies?

The term **epilepsy** is invariably used to refer to at least 50 different disorders and syndromes which have different causes, manifestations and outcome. That is why ALL generalities when talking about epilepsy (life-time treatment, danger from participating at sport activities, danger from video games...) are misleading. Such restrictions or constraints may apply to one form of epilepsy and not to the other.

Persons with epilepsy can excel in any aspect of daily life...

About Seizures and Epilepsies



In general, the repeated production of epileptic seizures requires a genetic predisposition, a brain lesion (due to a head trauma, a brain tumour, a vascular accident, an abnormal positioning of some neurons at the early stages of brain development...), or both.

In some cases, the underlying neurological disorder, responsible for the presence of epileptic seizures (example, a progressive mental deterioration due to a chronic infection in a child or Alzheimer's disease in an adult, complicated by epileptic seizures) may be a greater handicap than epilepsy itself. **However, epilepsy is not simply added to the pre-existing symptoms, and when they occur they multiply the handicapping effect of the underlying disorder and may increase the risks for accidents.** The impact of epilepsy is not only on the person with epilepsy, but also the family and indirectly the community are affected.

Rates of disease

- Epilepsy is a **chronic disorder** that affects people in every country of the world.
- There are over **50 million sufferers** in the world today, **85%** of whom live in developing countries.
- An estimated **2.4 million new cases** occur each year globally.
- At least **50% of cases begin at childhood or adolescence.**
- **70% to 80% of people with epilepsy could lead normal lives** if properly treated.

In developing countries, 60% to 90% of people with epilepsy receive no treatment due to limitations in health care resources and delivery, and due to social discrimination.

Treatment

Epilepsies can be treated by medications and/or surgery and some other more specialized treatments. Control of seizures is obtained for nearly two thirds of the newly diagnosed patients. **After some years of successful treatment with antiepileptic drugs, medication can be withdrawn in about 60-70% of patients without relapses.** For drug-resistant cases, epilepsy surgery represents an alternative of value. To perform surgery, specialized multidisciplinary teams have to identify a small region of the brain as responsible for the onset of seizures and make sure that irreversible damage of normal brain functions is avoided.

*70% to 80%
of people with
epilepsy could lead
normal lives
if properly treated...*

About Epilepsy and Sports

Social and economic impacts



Epilepsy is one of the world's oldest recognized conditions. Although the social effects vary from country to country, the discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves.

People with epilepsy can be targets of prejudice. The stigma of the disorder can discourage people from seeking treatment for symptoms and becoming identified with the disorder. In developing countries, three fourths of people with epilepsy may not receive the treatment they need.

According to the WHO:

- In both China and India, epilepsy is commonly viewed as a reason for prohibiting or annulling marriages.
- In the United Kingdom, a law forbidding people with epilepsy to marry was repealed only in 1970.
- In the United States, until the 1970s, it was legal to deny people with seizures access to restaurants, theatres, recreational centres and other public buildings.

TAKE HOME MESSAGES

- Epileptic seizures are **the manifestation of a large variety of diseases**.
- **Epilepsy is not one disease but a broad spectrum of disorders**, differing in terms of underlying cause, treatment approaches and outcome.
- **Early diagnosis of the precise form is essential** for the introduction of the most appropriate treatment.
- **Epileptic seizures can be controlled** either by drugs or by surgery and many of the epilepsies can be cured.
- **Social stigma and discrimination** are still on the frontline even in developed countries.
- **A better knowledge of what epileptic seizures and epilepsies really are will help people with epilepsy to reach their goals and achieve social integration in accordance with their ambitions and capacities.**

In developing countries, three fourths of people with epilepsy may not receive the treatment they need...

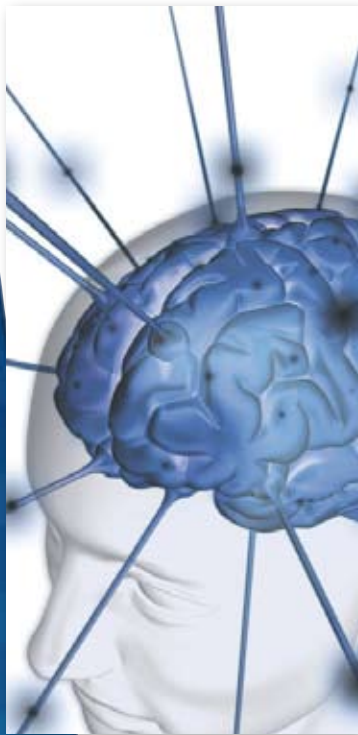
Some examples of websites where you can obtain more information about epilepsy:

<http://www.ilae.org/>
<http://www.lice.it/>
<http://www.lfce.fr>

<http://www.aesnet.org/>
<http://www.epilepsiemuseum.de/english/index.html>
<http://www.ligaepilepsie.de/>
<http://www.svenskaepsallskapet.se/>

About Epilepsy and Sports

Epilepsy, physical exercise and sports



For a number of years, people with epilepsy have been advised not to engage in vigorous physical exercise, out of fear that this could precipitate epileptic seizures or make their epilepsy worse. Although in some forms of epilepsy, seizures can be triggered by physical exercise, these forms are extremely rare and exceptional. By contrast, many studies conducted in the last 15 years have shown that, in general, physical activity does not worsen epilepsy and in many cases it may even improve seizure control.

For example, a study conducted in women with uncontrolled epilepsy in Norway showed that regular sessions of aerobic physical exercise for 60 min, twice weekly, for 15 weeks resulted in a significant reduction in the number of seizures.

This was associated with a reduction in health complaints, such as muscle pains, sleep problems, and fatigue, and with reduced levels of cholesterol and improved utilization of oxygen by the body.

In recent years, scientific research in laboratory models has confirmed that physical exercise does not aggravate epilepsy.

In addition, these experiments provide an explanation of why seizures can be improved by exercise: possible mechanisms include the production by the body of substances which prevent the occurrence of seizures, and indirect effects related to improved motivation, vigilance and alertness.

Apart from potential improvement in seizure control, exercise and sports in people with epilepsy bring benefits similar to those seen in people without epilepsy.



These include an improvement in general health, a greatly reduced risk of metabolic and cardiovascular diseases, and an overall sense of well being. Sports, particularly team events, are also important in building up self-confidence and facilitating inter-personal relationships and social integration. These are even more important in people with epilepsy, who often suffer from feelings of isolation and lack of self confidence.

The fact that physical activity and sports are good for people with epilepsy is not widely recognized. Data from several countries suggest that people with epilepsy participate in regular sports less frequently than those without epilepsy and they are generally less fit in terms of muscle strength, endurance and physical flexibility. In fact, many persons with epilepsy suffer from a considerable lack of physical fitness that impacts negatively on their general health and quality of life. This situation is likely to be a consequence of overprotection from parents or relatives and ignorance about the benefits of exercise and sports.

Sadly, insufficient participation of people with epilepsy in sports activities is also due in many cases to inadequate knowledge among health professionals and sport instructors.

Exercise and sports in people with epilepsy bring benefits similar to those seen in people without epilepsy...

About Epilepsy and Sports

Can people with epilepsy excel in sports?



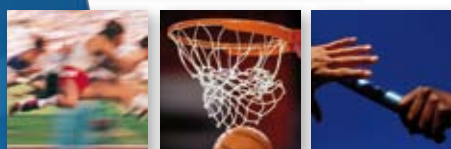
Persons with epilepsy can excel in any aspect of daily life. History and everyday experience teaches us that great artists, writers, entrepreneurs, doctors, actors and political leaders had, or have, epilepsy.

Men and women with epilepsy similarly have excelled in sporting activities: several top level athletes in sports as disparate as football, athletics and basketball have epilepsy.

Because of the stigma and prejudice which still surround the disease, many of these athletes have not publicly disclosed their condition.

However, there are important exceptions, and some athletes have become committed advocates in the fight against the ignorance, prejudice and discrimination that so often impact on the life of people with epilepsy.

These athletes have also been active in denouncing the unjustified restrictions that sometimes sports instructors or managers impose on people with epilepsy. One good example is Marion Clignet, a top level competitive cyclist who was twice silver medalist at the Olympic Games and over many years has won 180 races in different countries around the world, including 6 world championships. Her website (<http://marionclignet.com/home>) provides a lot of interesting information on how her epilepsy, instead of being an hindrance, represented for her a stimulus to improve physical performance and reach the highest levels of competitive achievement.



Can people with epilepsy engage in any sport, including football?

People with epilepsy can engage safely in the most sports. Even contact sports such as football (soccer), hockey, basketball, rugby and American football have not been shown to facilitate seizures, and people with epilepsy should not be precluded from participating in these events.

Water sports such as swimming and water polo are also safe if seizures are well controlled and direct supervision is present. Special care or caution is required with sports involving heights such as some subspecialties of gymnastic (for example, parallel bars, uneven bars) or horseback riding. Sports that involve extreme risk if a seizure should occur, such as hang-gliding, scuba-diving, downhill skiing, free climbing and car or motorbike racing are not recommended. Of course, additional limitations apply for people who have frequent seizures, and for those in whom epilepsy is accompanied by other disabilities.



Persons with epilepsy can excel in any aspect of daily life...

About Epilepsy and Sports



Other than minor levels of supervision, particularly for people whose seizures are not fully controlled, in most cases no special precautions are required when people with epilepsy engage in sports. It is wise, however, to pay some attention to avoid dehydration, loss of body salts, and hypoglycaemia, all of which can exacerbate seizure activity.

In some persons, seizures can be precipitated by deprivation of sleep or altered sleep-wake cycles, and their physicians can provide advice on how to minimize risks in these cases.

Football is the most popular sport in the world, and people with epilepsy should be encouraged to enjoy the pleasure of playing football with their peers.

The two matches involving participation of players with epilepsy organized in conjunction with the UEFA Under-21 Championship will show how such players can produce spectacular football and enjoy the game in the same way as young people without epilepsy. Although this is not well known to the general public, football players with epilepsy have been competing in top level leagues in many countries.



Benefits from participation in sports for people with epilepsy

Persons with epilepsy are entitled to live a normal life. As such, they should be encouraged to engage in the sports of their choice.

Benefits include not only a potential improvement in the control of their seizures, but also improved physical fitness, a reduced risk of obesity, protection against cardiovascular and metabolic diseases, and greatly improved self-confidence and well being.

Engaging in physical activities and sports also helps in preventing or counteracting the side effects of some medicines used to treat epilepsy, such as weight gain or increased fragility of bones.

For people who have infrequent seizures (or had no seizures for a long time), it is rare to have a seizure during exercise. If seizures are frequent, the probability of a seizure occurring during sports activities is higher simply due to chance. In any case, for safety reasons, it is recommended that school teachers and sports instructors know what to do (and what not to do) should a seizure occur. In particular, they should avoid placing anything in a person's mouth during a seizure, make sure that breathing is not obstructed, and remove any nearby object or situation that may result in physical injury.

In most cases no special precautions are required when people with epilepsy engage in sports...

About the International League against Epilepsy (ILAE)

The **International League Against Epilepsy (ILAE)** is the world's preeminent association of physicians and other health professionals working towards a world where no persons' life is limited by epilepsy.

Its mission is to provide the highest quality of care and well-being for the over 50 million children and adults who have this condition in the world.

Sometimes epilepsy occurs in isolation and sometimes in association with other conditions. Indeed, epilepsy can be associated with many maladies that affect humans, including HIV, and other infections, malnutrition, and environmental degradation.



The ILAE was founded in Budapest in September 1909 and therefore celebrates its Centennial this year. It has branches about 100 countries and it has over 15,000 members. It is a non-profit professional association, with official links with the World Health Organization (WHO). More information can be found in the website www.ilae.org.



Concern for involvement of lay persons occurred early in the development of ILAE, and evolved into the creation of a sister organization, the **International Bureau for Epilepsy (IBE)**. The IBE is an important advocacy group, campaigning for improvements and developments in epilepsy care and services worldwide by raising awareness of epilepsy and influencing opinion leaders and policy makers. More details can be found on its website www.ibe-epilepsy.org.



The partnership between these two bodies is characterized by a closeness and productivity that may be unique among international health-oriented organizations.

The ILAE pursues the following aims:

- To advance and disseminate knowledge about epilepsy.
- To promote research, education and training.
- To improve services and care for people with epilepsy, by improving prevention, diagnosis and treatment.
- To change the way people with epilepsy are often perceived in their environment, by fighting the prejudice, stigma and ignorance about the nature of epileptic disorders.

The ILAE operates through regional commissions which include Europe, North America, Latin America, Asia and Oceania, East Mediterranean, and Africa. Europe is the largest region in terms of branches (Chapters), which are present in 42 countries. With very few exceptions, every country that plays in the UEFA Championships is also represented by a national Chapter in the European ILAE region. The ILAE Commission on European Affairs, the administrative body of the ILAE in Europe, is enthusiastically contributing to this event, which can demonstrate that people with epilepsy can and should live a normal life and engage in all activities of society, including sports. We thank warmly UEFA for offering our community such a great opportunity to defend the cause of all persons living with epilepsy.



About the UEFA...

The **Union of European Football Associations** (French: Union des associations européennes de football) is the governing body of European football.

UEFA represents the national football associations of Europe, runs European national team and club competitions, and manages the prize money, regulations and media rights for these competitions.

UEFA is one of six continental confederations. UEFA was founded on 15 June 1954 in Basle, Switzerland, following discussions between the French, Italian and Belgian FAs. The headquarters was in Paris until 1959, when the organisation moved to Berne. Its administrative centre since 1995 has been in Nyon, Switzerland. UEFA was initially made up of 25 national associations. There are now 53.

The current UEFA president is Michel Platini. UEFA is a representative democracy. The administration and regulation of football is organised in a pyramid structure, with FIFA, the world governing body, followed by UEFA, the European governing body, and finally the national football associations, the governing bodies at domestic level. Subsidiarity is a guiding principle in this hierarchy, with the international bodies regulating only where international, or in some cases, worldwide action is required.

In addition to the national football associations who are members of UEFA, there are a variety of other organisations who contribute a great deal to football and whose interests need to be suitably recognised. Clubs are the bedrock of football at all levels and leagues are important in competition organisation and administrative management at national level. There is wider acceptance now that players' interests need to be taken into account in football administration. And we should not forget that the popularity of European football is demonstrated through the enthusiasm of football fans across the continent.

**UEFA has therefore formulated the following vision of success:
«A united European football family working together to improve enjoyment of the game.»**

UEFA itself has a philosophy of "football first". From its work in staging top-class European competitions for national teams and the best club competitions in the world, right through to its work with national associations to develop coaching and grassroots football, UEFA is very active in promoting and developing European football.

The role of UEFA – its core mission – can be expressed as follows:

«To create the right conditions for the game in Europe to prosper and develop.»

UEFA plays an integral role in maintaining and improving the health of the game – but its activities are by no means restricted to the playing field. Nothing reaches out to people as football does, which is why the game has a responsibility to be a role model.

About the UEFA...

Through its social investments, UEFA promotes the social role of football and addresses key social issues that are relevant to football, the objectives being to strengthen the health and integrity of both European football and European society as a whole, to build on football's role as a positive force in society and to enhance UEFA's ability to shape that force.

Respect underpins all UEFA activities. Respect is a key principle in football. Respect for the game, respect for diversity and respect for the environment.

The curtain-raiser matches with teams from the International League Against Epilepsy on the occasion of the two UEFA European Under-21 Championship semi-finals will be the platform on which to underline the message:

Football is open to all abilities.





CONTACTS

Contact UEFA

Route de Genève 46 - CH-1260 Nyon 2

mediaservices@uefa.ch

For further information:

UEFA Media Services +41 (0)848 00 27 27

www.uefa.com

Contact ILAE

Ass. Professor Alexis ARZIMANOGLOU

Member of the ILAE Commission on European Affairs and President of the French League against Epilepsy Institute for Children and Adolescents with Epilepsy (LFCE) - IDEE, University of Lyon

aarzimanoglou@orange.fr

Professor Torbjörn TOMSON

Chair of the ILAE European Advisory Council and member of the Commission on European Affairs Karolinska University Hospital, Sweden

torbjorn.tomson@karolinska.se

Phone +46 851773705