Stand Up For Epilepsy
San Diego photo-shoot: a personal odyssey

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ABSTRACT – Stigma towards epilepsy results in barriers to social integration, education, employment, and marriage, with increased divorce rates. There is a societal need to realise that many persons with epilepsy (PWE) lead normal lives and can be highly educated with effective employment. Integration of PWE into sports is therapeutic both for PWE (decreased seizure frequency, decreased comorbid conditions, and increased psychosocial skills) and society. Stand Up For Epilepsy (SUFE), overseen by the ILAE Task Force on Sports and Epilepsy, is an international project in which action photographs with PWE were taken as a means to destigmatise epilepsy. This autobiographical narrative describes how SUFE initiated effective athlete-PWE interactions with positive PWE, athlete, and parent responses. Expansion of SUFE is recommended to further destigmatise epilepsy. Participation in SUFE can serve as a personal odyssey for PWE.

There was once a boy (the first author) who had a first seizure at age 12 and was diagnosed with epilepsy. A person with epilepsy must navigate life through societal barriers which should not exist, but do. Now, at the age of 64, he recalls with warmth the care of a loving mother who helped guide her son through the social and educational stigmas of the 1960s-1970s (Kaufman, 1994). In retrospect, he realises why parental protection was a necessary defence against stigma in his youth. He further realises both what was overcome in those early decades and how he has come full circle in his personal odyssey. This autobiographical commentary addresses his initial North American experiences in the Stand Up For Epilepsy (SUFE) project. Athletes play an iconic role in modern society, especially for...
children and adolescents. As such, it is not surprising when professional medical societies seek the aid of athletes in order to promote the social well-being of patients with varied illnesses. An individual athlete’s love for sport may narrowly ennoble the individual as an athlete, however, an athlete’s interaction with and care for patients with illnesses helps to destigmatise illness while ennobling the athlete as an individual, the patient, and society. With athletes, it may be possible to bring those with illness “out of the shadows”.

The Sports and Epilepsy Task Force of the International League Against Epilepsy (ILAE) was created with the intent purpose to address recommendations regarding sports for persons with epilepsy (PWE). Sports, recreational activities, and physical exercises are therapeutically important in order to decrease seizure frequency, restrict comorbid conditions, and improve psychosocial skills (Regan et al., 1993; REST-1 Group, 2000; Dubow and Kelly, 2003; Howard et al., 2004; Knowles and Pleacher, 2012; Arida et al., 2013). A policy statement by the American Medical Association restricted athletic activities for PWE: a) if seizures were not well controlled, and b) if the activities were contact sports (American Medical Association Committee on the Medical Aspects of Sports, 1968). This policy has since been reversed in order to permit all PWE to participate in athletics (Howard et al., 2004), however, the inherent damage from the restrictive policy has had far reaching effects for open PWE participation in sports. PWE may be elite athletes who, because of societal ignorance, are hindered or even prohibited from participation in competitive sports. When cyclist Marion Clignet was queried regarding discrimination in sports, she responded: “I experienced discrimination once because of my epilepsy, when the US team coach was choosing the team to compete at the world championships in 1990. I was clearly one of the strongest members of the group being selected but was told that I couldn’t participate because having epilepsy made me a risk (Chapman, 2007)”. As she had dual citizenship, Marion moved to France where she was selected for the French national team and ultimately won six world championships and two Olympic silver medals.

One important project of this ILAE Task Force is the SUFE project, wherein PWE are photographed with sports figures as a means to destigmatisé epilepsy. These photographs are intended to be exhibited at different international epilepsy congresses and published in a book. The first exhibit was at the 10th European Congress on Epileptology in London with further exhibits at the 66th American Epilepsy Society Annual Meeting in San Diego and the 30th International Epilepsy Congress in Montreal. Many of these photographs can be accessed and viewed globally online through social networks and websites.

Method

This paper is a narrative review of the authors’ involvement in the SUFE project with emphasis on the San Diego photo-shoot. The senior author (first author) is a member of the ILAE Task Force on Sports and Epilepsy and supervised the North American SUFE photo-shoots. The junior author (second author) volunteered as a delegate to the SUFE project and was the photographer for multiple photo-shoots. For the ten photographs (figures 1 to 10) from the different photo-shoots mentioned hereafter, see Appendix 1.

Results

During a seven-month time period (12/11-6/12), the senior author actively recruited PWE and elite athletes to partake in the SUFE project. During this period, the senior author sent/received approximately 750 emails plus extensive telephone contacts regarding the SUFE project. He quickly learned that there were difficulties in recruiting PWE and athletes: 1) though the project was to destigmatisé epilepsy, PWE were not always eager to participate due to their perception of epilepsy and concern that others would learn of their epilepsy; 2) though some epileptologists were interested in assisting, many were not, and very few agreed to supervise a photo-shoot; 3) one national sports federation viewed SUFE as a form of sponsorship and would not disseminate information regarding this project to their athletes but referred the senior author to the athletes’ agents; 4) another national sports federation was focused on how much their athletes would be paid; 5) athletic coaches, representatives, and agents did not respond positively toward email and telephone contacts when seeking involvement of their athletes in this humanitarian project; and 6) only a limited number of athletes responded to telephone and email contacts to create the North American photo-shoots.

The senior author turned to his educational roots to find interested athletes, the Ivy League where he received his AB (Columbia) and AM (Harvard). The first photo-shoot involved Princeton undergraduate, Sandra Fong (3-position rifle, 2008 Beijing Olympic Games) (figure 1). Next, he sent emails asking “can you help a fellow Columbia graduate” with fruitful responses. Two Columbia athletes addressed the origins of his personal odyssey. Daria Schneider (Pan American Games saber team gold medalist and World Championship saber team bronze medalist) fenced with the senior author in the same building where he learned to fence as an undergraduate (figure 2). The junior author was the photographer for the photo-shoot and was already quite familiar with Columbia as
both often went there for father/son outings to watch different sporting events, including swimming. This led to the second Columbia alumna, Cristina Teuscher (4 × 200-metre freestyle relay Olympic gold medalist, 1996 Atlanta Games and Olympic bronze medalist, 200-metre IM, 2000 Sydney Games) whom both authors had witnessed competing as a Columbia undergraduate. Now, years later, she eagerly participated in the SUFE project while asking to learn more about epilepsy as an illness as well as how to be supportive of those with epilepsy. For PWE, doing one’s best and proving that one can do as well as, or better than, those without epilepsy are constant issues. Cristina’s comment to the participants in the photo-shoot (swimmers with epilepsy, senior author as supervisor and junior author as photographer) was telling, for she, at one time, held all of the Columbia women’s pool records: “I am glad my records are being broken, for records are meant to be broken; it means that women are getting faster.” That PWE do not have boundaries and can be swimmers was best expressed to her by the PWE in the photo-shoot, a former collegiate swimmer who has become a swimming coach (figure 3).

To find more athletes and athletic teams, the senior author approached the Chula Vista Olympic Training Center (CVOTC), outside San Diego. The media relations coordinator at CVOTC sent an email to all athletes explaining SUFE, thus permitting all athletes to reply individually regarding their participation in SUFE. Two interested athletes (field hockey and archery) rapidly responded and then recruited team members to participate. Contacts with local neurologists led to the participation of two PWE in the San Diego community, which quickly expanded to eight teenage PWE. Shortly before the planned photo-shoot, it was learned that one PWE played rugby; since the rugby teams were in residence at CVOTC, the senior author requested the media relations coordinator to contact the rugby teams. On one Friday afternoon, over the course of five hours, the San Diego photo-shoot occurred and included nine PWE including the senior author, 24 elite and Olympic athletes from five national teams (USA Men’s Rugby Sevens, USA Women’s Rugby Sevens, USA Women’s Field Hockey, USA Women’s Archery, and USA Men’s Archery), and five photographers. Approximately 1,400 pictures. To witness the athletes and PWE play together was a joy for all who participated that sunny afternoon. There were many memorable moments: 1) the captain of the USA Men’s Rugby team being tackled by a PWE (figure 4); 2) the USA Women’s Rugby Sevens playing tag with PWE and spending time with each individual PWE (figure 5); 3) the USA Women’s Field Hockey team playing one-on-one with PWE (figure 6) and then teaching them how to celebrate after a goal; and 4) the USA Archery team members instructing each PWE how to hold the bow and arrow properly, address the target, and then witness the results of a well-aimed shot (figure 7). What was so impressive was how much individual time was spent by each athlete with different PWE – no one was overlooked or excluded and all were part of this festive afternoon.

Further North American photo-shoots of table tennis were held and included Olympian Lily Yip (1992 Barcelona Games, 1996 Atlanta Games), two current national team members (her children Judy and Adam Hugh), and a Maccabiah medalist (Barry Datel). These photo-shoots were special, for the senior author was the PWE and the junior author, who plays competitive table tennis, was the photographer (figure 8). In all, the North American photo-shoots involved more than 10,000 miles of travel for the senior author, 35 athletes, 11 PWE, eight photographers, and approximately 2,100 pictures.

At the San Diego photo-shoot, parents’ comments summarised the significance of SUFE and the senior author’s role: “You don’t know how special this is for these children... they are playing with Olympians as people; no one cares about their epilepsy. Look at you: you have epilepsy and look how far you have gone—you are a doctor/psychiatrist, on an international task force, competed internationally, and have a gold medal (cricket, 1989 Maccabiah Games). Do you have any idea what a representative and role model you are for these children about how far a PWE can go? You have proven there is no limit.” The odyssey was completed when one parent simply stated: “Do you know how proud your mother is of you? Today you really made your mother proud to be a mother.”

A final photo-shoot with an elite hammer thrower (figure 9), following completion of the poster presented at the American Epilepsy Society (AES), took place at the AES Annual Meeting in San Diego when several of the photographed PWE and their parents visited the SUFE exhibit to appreciate their earlier efforts and enjoy the global photos. The authors discussed the different North American photo-shoots, the issues involved with different PWE, and the athletes associated with SUFE. During this reunion, all PWE expressed how significant it had been for them to participate in the earlier San Diego photo-shoot and how special it was to be part of SUFE. Their realisation of how global SUFE had become truly made them appreciate how important their involvement was. These PWE felt special when they entered the Exhibit Hall and viewed a video of “The North American Stand Up For Epilepsy Experience” (a video loop of more than 700 photos was created by the authors). One PWE had felt overwhelmed when told by his mother of the size of the AES meeting; but when told that the senior author would be present, he suddenly became eager to come for “I want to see Dr Kaufman again, he means so much

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to me. Do you think he would spend time talking to me?" An understanding of the relationship between the senior author and this PWE is best described pictorially (figure 10).

Discussion

Why is there a need to destigmatise epilepsy? Regrettably, both society and the medical profession do not recognise the significant lifetime prevalence of this illness. A recent Institute of Medicine report estimates that one in every 26 persons during their lifetime will be diagnosed with epilepsy (England et al., 2012). In western developed countries, the diagnosis of epilepsy, even when controlled, has: 1) prevented some students from participating in high school/university/graduate studies in sciences; 2) limited admission to study certain specialised subjects, including medicine; 3) barred access to specific employment with resultant under-employment; 4) impacted psychosocial interactions, increased divorce rates, and has even been used as the basis for monitored visitation of children during divorces (Kaufman, 1994; Jacoby et al., 2005; Breeden et al., 2008; Parfene et al., 2009; Maslow et al., 2011; Geerts et al., 2011; England et al., 2012). The global stigma of epilepsy is even greater in under-developed countries where: 1) epilepsy is not considered an acceptable illness (certain cultures refer to supernatural and witchcraft aetiologies and epilepsy is considered to be contagious); 2) PWE who disclose their epilepsy may suffer “loss of face”; 3) epilepsy is felt to shame the family with resultant stigma by association; 4) PWE have significantly less education and are under-employed; 5) decreased marriage rates and increased divorce rates are directly related to epilepsy; and 6) PWE are excluded from normal interactions leading to isolation and decreased self-esteem (Baskind and Birbeck, 2005; de Boer et al., 2008; Jacoby et al., 2008; Li et al., 2010; Atadzhanov et al., 2010; Kim et al., 2010; Goel et al., 2011). Clearly, cultural competence is an important theme to consider in order to understand stigma associated with epilepsy, to effectively treat epilepsy, and to educate healthcare professionals (Fadiman, 1997; Fox, 2005; Malina, 2005).

How can SUFE destigmatise? Photographs of elite athletes with PWE cannot accomplish such a purpose alone. The photographs serve as the substrate for future dialogues regarding epilepsy and sports. The global efforts of SUFE (photo-shoots from six continents, 30 countries, and approximately 150 athletes) speak to what can be accomplished. The fact that SUFE is accessible online means that not only athletes and PWE can see these images, but the entire world can view them. As such, these images can be a global educational tool. Furthermore, the communications that occurred during the photo-shoots had significant impact upon both the athlete and the PWE. For the PWE, such interactions imply respect and acceptance both as a person and as an athlete. In the North American photo-shoots, the athletes shared email addresses with PWE. For the elite athlete, many were very eager to learn more about epilepsy, what they could do to assist PWE, and how they could enhance their sporting careers. The senior author, who supervised the North American photo-shoots, was able to educate elite athletes at the photo-shoots and through email correspondence. Even though several elite athletes have openly discussed the impact of epilepsy on their lives and sporting careers, most athletes in the North American photo-shoots were surprised to learn that world champions, world record holders, and Olympic medalists are PWE (Dai Greene [400-metre hurdles, world champion]; Florence Griffith Joyner [world record holder: 100-metre sprint {10.49 sec} and 200-metre sprint {21.34 sec}; Olympic medalist (three gold medals and two silver medals: 100-metre sprint, 200-metre sprint, 4 × 100-metre relay, and 4 × 400-metre relay; 1984 Los Angeles and 1988 Seoul Olympic Games}); Chanda Gunn [bronze medal, ice hockey, 2006 Turin Olympic Games]; and Marion Clignet [six-time world champion cyclist with two Olympic silver medals, 1996 Atlanta and 2000 Sydney Olympic Games]).

For the senior author, SUFE was an ILAE project with a very personal meaning. From a sporting perspective, he had played cricket competitively at local, regional, and international levels (gold medal, cricket, 1989 Maccabiah Games) without ever having had a seizure during practice or competition, yet had never shared the fact he had epilepsy with team-mates. SUFE gave him a voice to discuss his social, athletic, and academic experiences with other PWE and elite athletes. From an academic perspective, San Diego had much personal significance, for it was a reminder of a key educational barrier to medical school which is described in a letter written by the senior author to his mother “somewhere over Kansas”. The letter was written in January 1970 and described the excitement of flying to UCSD for his third interview at the same medical school. He had been advised by the neurologist who had already interviewed him twice that “the prejudice of the Admissions Committee must be overcome”. The Admissions Committee only needed to persuade one more member that PWE could attend medical school for his gaining admission to the Class of 1974. He can close his eyes and remember that flight, the excitement, and the interview. For all of his fervor, he was not admitted to that school – in fact, the only medical school that accepted him was Washington University School of Medicine in the MD/PhD program. He recalls
the classic phrase from Professor Landau, Chairman of Neurology, who stated: "Just imagine how far he might go if his seizures are ever controlled (AB summa cum laude Columbia University; AM in theoretical organic chemistry Harvard University)." Today, nearly 43 years later after that flight to San Diego, as a tenured professor of psychiatry, he presents this article, co-written by his son. He has withstood stigma toward epilepsy in the most unimaginable ways throughout life (Kaufman, 1994) and has raised a son who does not believe in any barriers based on race, ethnicity, religion, or illness. The involvement in the San Diego photo-shoot and presentation of the SUFE project in San Diego truly represents a full circle in a personal odyssey.

**Conclusion**

There is a societal need to realise that many PWE lead normal lives and can be highly educated with effective employment. Integration of PWE into sports is therapeutic both for PWE and society. SUFE initiated athlete-PWE interactions with positive PWE, athlete, and parent responses. Expansion of SUFE is recommended to further destigmatise epilepsy. Participation in SUFE can serve as a personal odyssey for PWE.

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**References**


Appendix 1
A selection from the San Diego photo-shoots showing PWE and elite athletes partaking in the SUFE project.

Figure 1

Olympian Sandra Fong (2008 Beijing Games; team gold medal and world record, 2010 World Shooting Championships, 50-metre 3-position rifle) explains the aiming process as she teaches Kenneth Kaufman (PWE; gold medal, cricket, 1989 Maccabiah Games) the prone rifle position.
Photographer: Katherine Elgin. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.

Figure 2

Daria Schneider (gold medal, team saber, 2009 and 2011 Pan American Games; silver medal, individual saber, 2009 Pan American Games; bronze medal, 2011 and 2012 World Team Saber Championships) discusses fencing grip with Kenneth Kaufman (PWE; gold medal, cricket, 1989 Maccabiah Games) and Gil Seda (PWE).
Photographer: Nathaniel Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.
Olympian Cristina Teuscher (gold medal, 4×200-metre freestyle relay, 1996 Atlanta Games; bronze medal, 200-metre individual medley and Captain of US women’s team, 2000 Sydney Games) shares the lane divider with Annie Weeks (PWE; current swimming coach and former co-captain, St Joseph College of Connecticut). Photographer: Nathaniel Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.

Shalom Suniula (Captain, USA Men’s Rugby Sevens; bronze medal, 2011 Pan American Games) tackled by Tristan Kasa (PWE). Photographer: Shannon Kasa. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.
USA Women’s Rugby Sevens in a team photo with Rachel Chiecuto (PWE), Samantha Mendoza (PWE), Kenneth Kaufman (PWE; gold medal, cricket, 1989 Maccabiah Games), Tristan Kasa (PWE), and Cael Carmichael (PWE). Photographer: Shannon Kasa. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.

Olympian Michelle Kasold (gold medal, 2011 Pan American Games; 2012 London Olympic Games; 123 caps) playing one-on-one with Maggie Carey (PWE). Photographer: Geovanna Soler. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.
Figure 7

Olympian Miranda Leek (silver medal, individual and team competition, 2011 Pan American Games; 2012 London Olympic Games) instructs Emma Berholtz (PWE).
Photographer: Kenneth Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.

Figure 8

Photographer Nathaniel Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.
**Figure 9**

Britney Henry (elite hammer thrower) shares her hammer with Ryan Spink (PWE).
Photographer: Kenneth Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.

**Figure 10**

Kenneth Kaufman (PWE; gold medal, cricket, 1989 Maccabiah Games) hugs Aidan Miller (PWE).
Photographer: Nathaniel Kaufman. Reproduced with permission from the ILAE Stand-Up for Epilepsy Photographic Collection of Athletes and People with Epilepsy.