

by Rita Sanderson

On April 9th, 2002 I had the good fortune of attending the New England Theatrical Premiere of the highly-acclaimed film about CFIDS/ME, *I Remember Me*. This program was organized by the Massachusetts CFIDS/ME & FM Association and included a guest appearance and presentation by the film's Director, Kim Snyder. The Premiere took place at the Brattle Theatre, a relatively small but cozy movie revival house in Cambridge, where many documentaries, independent and foreign films are the mainstay. The 250-seat theater is often referred to as Boston's unofficial film school. The theatre was filled to capacity for the first showing.

This was a very compelling and informative account of "life with CFIDS/ME." This 74-minute documentary film was directed by Kim Snyder, an experienced filmmaker from New York, and a person with CFIDS/ME. This film marks Kim's directorial debut. Her film credits include documentaries i.e. Oscar-winning film *Trevor*, and feature films i.e. *Home for the Holidays*. The film focuses on Kim's personal struggles with CFIDS/ME and her pursuit of answers over a 5+ year period. Snyder's reflections and revelations about her own experience took on the form of an interview that was intertwined with stories of other people with CFIDS/ME, observations by a variety of clinicians and researchers, and visits to key locations. In between the dialogue and these clips, a mixture of scenes were interposed, such as the storminess of the sea, seclusion by the riverside, the fury of a strong wind tearing across the fields, and buildings crumbling to the ground—visual images that conveyed to me what I believe were Snyder's innermost feelings and suffering.

Snyder's quest for information took her to Lake Tahoe, Nevada, site of one of the first known clusters of this mysterious illness during the mid-1980s, where an extensive conversation with Dr. Dan Peterson was recorded and presented in segments. Dr. Peterson showed genuine concern about people who had been well, suddenly became ill, many still remain ill, and those who had taken their lives over the years. He also expressed disgust with the sloppy investigation conducted by CDC and NIH officials who left skeptical that anything unusual had taken place. A clip was also shown of Dr. David Bell who spoke about a similar occurrence in upstate New York.

A number of other doctors were interviewed including Drs. Nancy Klimas, Peter Rowe, D.A. Henderson, and Alexis Shelekov, and several others, all of whom strongly supported the serious, complex nature of this illness. They reported on their clinical or research experiences.

Commentary by Dr. William Reeves, former branch chief of the CDC, was also included regarding the diversion of funds from CFIDS studies and acknowledgment that CFIDS has become a major health problem. Contrary to these opinions, Dr. Peter Manu, an ill-informed doctor, was filmed at one of the CFIDS conferences saying that he believed CFIDS was nothing more than a form of hypochondriasis, where patients and advocating doctors have been trying to "create" or turn it into a "real" illness.

Another comparable, but earlier outbreak of a CFIDS-like illness occurred over 40 years ago in Punta Gorda, Florida. Snyder was able to identify and meet with several of the women who had become ill but they had no idea, until recently, what had happened to them. Apparently, a medical article had been published about their cases but no one had ever gotten back to them. There were three other significant interviews. One was with Michelle Akers, Olympic gold medallist and world's top soccer player, who spoke with a lot of emotion and frustration about her experience (she has since had to retire from soccer due to CFIDS.). Another one was a rare discussion with Blake Edwards, a famous Hollywood film director ([Breakfast at Tiffany's](#) , [Days of Wine and Roses](#)

, *Pink Panther*

) and husband of singer Julie Andrews. Edwards was very candid but cynical about his struggles with this illness.

The most touching of all the interviews was the story of Stephen Paganetti, a young high school student from Connecticut. At the age of sixteen, this boy had a very abrupt change in his health and quickly became bedridden for over 2 years. He had to be home-schooled and have all his daily needs taken care of by his parents, including being fed through a tube. The film recorded the exhausting preparation for his graduation where he was brought by ambulance while receiving IVs and oxygen. He was wheeled on a gurney to receive his diploma. Later on, he was surrounded by many of his former classmates, some of whom made thoughtless remarks. None of them had ever paid him a visit at home during that time.

The film moved reflectively from past to present through numerous scenes, people and places capturing certain experiences that I feel effectively portrayed the kind of roller coaster ride Kim Snyder and most of us have been on. All the tests, brush-offs by local doctors, ridicule by other people, and the overall frustration, isolation, and pain are situations that I, and my peers, could readily identify with (with the exception of the severity of Stephen's case). A segment was included regarding suicide. Each of the leading CFIDS/ME doctors admitted to having lost several patients over the years, mainly due to pain, and in one case, driven by the total disbelief and disregard by local doctors that made this individual's life unbearable.

At the end of the film, the audience enthusiastically applauded Kim Snyder and expressed great appreciation for all the seven years of hard work that she put into making and marketing this film. It was a true labor of love! It was also a critically-acclaimed success garnering the following

awards: Winner Best Documentary, People's Choice Award, Denver Film Festival; First Runner Up, Sarasota Film Festival; and Honorable Mention, Hamptons Film Festival.

Patients could say that they are already intimately familiar with this illness, so why go and pay to see a movie about it? All I can say is that people went to show their support for an incredible accomplishment by someone who has walked in our shoes. This film also provides a great opportunity to educate family and friends who still don't understand what CFIDS/ME is and how it impacts our life. Most importantly, our patient community now has a great new tool to educate medical professionals and others who don't quite get it. We thank Kim Snyder for her enduring legacy! For most of us, it took us one day (and perhaps another day or two of recovery) to see the results of Snyder's investment of 5+ years in the making of this film. She has been traveling to film festivals and screenings over the past year or more, making it a seven-year journey.

A lengthy Q & A session with Kim took place after the first showing of the film. She responded to dozens of questions from the audience who praised this award-winning film. She recounted her now seven-year experience working on this film. A couple of questions were raised concerning a few aspects that may have been overlooked in this film. One is the "poverty" that is often brought on by this illness, and the other is the need for a more accurate representation of the "ethnic" groups afflicted by this illness. Viewers felt these aspects ought to have been included. Other questions included why Fibromyalgia had not been mentioned. Snyder answered that her research used the terms/definitions coined during these early outbreaks that she had investigated. She recognizes that FM and CFIDS are intertwined, and she acknowledged having both. In response to one of the last questions, she announced that after 7 years, she found herself doing considerably better—for no explainable reason other than "luck."

This film was aired several times during April, 2002 on the Sundance Cable Channel.

Rita Sanderson is on the Board of the Massachusetts CFIDS/ME & FM Association. Special Thanks to both Rita and her daughter Tamara, as well as our heart-felt thanks to Kim Snyder for this great film.