

Film Review

So Much So Fast

Directed by Steven Ascher and Jeanne Jordan

Reviewed by Elaine Adler

Some describe *So Much So Fast* as an inspiring film documenting the progression of symptoms of amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease. While this is true, it is also the story of the love and support of an ordinary family responding in extraordinary ways to a devastating situation. Even while watching the degeneration caused by ALS, this is a story of hope and grace under fire.

ALS is a disease that rapidly weakens the body's neuromusculature. It isn't pretty. It can happen to anyone. When the diagnosis comes for good-looking, bright, capable Stephen Heywood at the age of 29, he and his family turn their lives upside down to help not only him but others who will come after him.

Directors Steven Ascher and Jeanne Jordan had a personal investment in telling this story after watching Jordan's mother succumb to ALS a few years earlier. They understood the fine nuances and impact of this debilitating disease. Granted the privilege of access to intimate family moments, their heightened sensitivity informed their ability to paint a vivid picture of how ALS affects all involved.

Old photographs depict a happy and successful family, with three brothers who have a good time together. They are verbal and love to play games. As young adults, they continue a tradition of "video-game night," even when one lives across the country. They are competitive, bright, and quick. With Stephen's diagnosis, they seamlessly translate all their love, closeness and energy into finding ways to support him.

Their father is an MIT professor of engineering; their mother a therapist. Older brother Jamie, who has a mechanical engineering degree from MIT, is energetic, charismatic, and a mover and shaker whose thought processes are on the cutting edge. Without a blink, he quits his job to devote his life to finding a cure for his brother. Youngest brother Ben, also an MIT-trained engineer, jumps on board. Without medical training, Jamie becomes an expert in ALS, including progression of symptoms, how the nervous system functions, and pharmacological research methods to test potential drugs. He discovers that ALS is an "orphan disease," one that lacks sufficient incidence for pharmaceutical companies to spend money on. As a medical outsider, he brashly initiates the ALS Therapy Development Foundation (ALSTDF). He seeks funding, creates a lab to test a variety of drugs on ALS-induced mice, and tries to convince researchers in academia and pharmaceutical houses to help. One researcher proposes that either Jamie is the next Einstein or just nuts, and his hunch is that it is the former.

Shortly after his diagnosis, Stephen marries his sweetheart. He remains active by applying his design and building skills to remodel their house. No longer able to wield tools, he oversees each detail while training others to carry out his vision. Their son is born just a few months after Jamie and his wife have a little girl. Watching these two cousins growing up during the three-year filming period helps mark the passage of time.

Before his son learns to crawl, Stephen is already losing control of his hands. In one scene, as they are casually eating and shmoozing, we watch one brother feeding one of the babies while the other spoon-feeds Stephen. Because lending a helping hand comes so readily to them, one has the impression that the brothers are not even aware of the comparison; yet, beneath the surface, the film's directors subtly convey this juxtaposition in a touching way.

When his walking becomes arduous, Stephen comments that he never thought he'd get bored walking across a room. He's ecstatic when his \$26,000 fully loaded wheelchair arrives so he can speed down the road and do whirlies. His joy at this freedom is contagious. In time, his weakened hands will no longer allow him to work the controls.

During family vacations, everyone pitches in to ensure that Stephen can participate. They effortlessly make accommodations for him. No one complains. No one makes a big deal about it. There is no shame. How extraordinarily natural it all seems. When they approach stairs to climb up to the Acropolis, his brothers hardly break stride as they bend down and scoop him up in his wheelchair. In a swimming pool, they outfit Stephen in a life jacket and weave a plastic tube through the shoulders to help support his head.

As various tasks become more difficult for Stephen, Jamie's prodigious problem-solving skills are put to the test many times over as he develops technology to extend Stephen's ability to function. When Jamie realizes there is too much friction between the computer mouse and table for Stephen's hand to move it, he designs and builds a metal track with a board that seems to float on ball bearings. With the mouse attached, Stephen is back in touch with the world through his computer.

Eventually, even the track is too difficult for him. His speech is no longer intelligible and his thoughts are trapped inside his head with no way out. His loss of communication is visibly frustrating and painful to all. In addition to affecting his capacity to convey his needs, it diminishes friendly interaction for this communicative family. Jamie again rises to the occasion, devising a system that allows Stephen to use the one thing he can still move. On his wheelchair headrest, Jamie designs computer dials that Stephen operates by tapping with slight movements of his head. The taps select letters on the computer screen, and the words spelled are translated into spoken speech. It is amazing to see how quickly he masters this device and how fast the words come out.

Through the years, Jamie continues to work tirelessly to ward off the inevitable for his beloved brother. It is an obsession—a mission. His lab is constantly on the brink of financial disaster. The cure he longs for eludes him. In addition to everything else on his plate, he reaches out to others with ALS, offering seminars to share what they are learning at the lab. The price Jamie pays for his relentless efforts on behalf of ALS and his brother is the break-up of his marriage,

The Heywoods never seem to lose hope. Stephen's will to live is persistent. When he can no longer swallow, a feeding tube is inserted, and we watch his mother adeptly pour coffee in so he can "get a buzz." Finally placed in a respirator and immobilized, Stephen expresses his desire to stick around because he doesn't want to miss a moment of watching his son grow up. Stephen's wife, with her beautiful smile and loving care, admits that she can't let down her front of positive optimism. Even Stephen jokes that they suffer from "acute denial of approaching reality."

In the last scene, the family celebrates Ben's wedding on the beach. When it is time to leave, Stephen's brothers and friends lift the chair on which he's been sitting. Once aloft, we become aware that the chair is attached to long poles, much like a pharaoh's sedan chair. The camera backs away for a long shot, and it is not lost on us that the allusion created is one of pall bearers carrying him across the sand. The image stabs at the heart.

I admit to approaching this movie with some trepidation of depression. I was only too aware that I was sitting in a

theater in the same community in which the Heywoods live. What a gift to find a beautifully conceived, poignant, sometimes funny, always heartwarming engagement with this family that was put to the test and found remarkable. The entire Heywood clan, through their willingness to document their family's saga, leaves an inspiring legacy for others. Would that all in need of care have the loving and supportive network, the natural ease, the mechanical know-how, and the positive outlook of their experience.

There are many lessons in this film for all of us. Yes, there are the obvious lessons of maintaining hope in adversity, of reaching out with positive support, of thinking outside the box for treatment and ways of coping and adapting. Yet, the big lesson might be to maintain dignity and respect for those whose bodies cannot do what we expect them to do, which allows them to feel dignity for themselves.

So Much So Fast has the ability to raise consciousness that will apply pressure for recognition by pharmaceutical researchers for this terrible disease. Unfortunately, it probably will not show at big movie theaters, and it may not get the coverage it deserves. If there are no planned screenings in your area, you might consider asking your favorite off-beat theater to book it. If it is in a nearby theater, take your family and friends and go celebrate life with them.

Note 1:

Just ten days before I saw So Much So Fast, Jamie announced that his brother Stephen had unexpectedly passed away in the early morning of Saturday, November 25, 2006, just two days after their family Thanksgiving celebration. His vent somehow disconnected during the night, and he went into cardiac arrest. Poignantly, one of the comments that Stephen made during the film was a concern that something would happen to him while alone, with no one to help him. He was resuscitated just long enough to keep his body alive for surgeons to remove his kidneys, which were immediately implanted in two patients who will benefit from them. His passing puts an end to an experiment to test the safety and effectiveness of potential technology. Just a month earlier, a device was implanted in his brain to pick up neural signals that might be triggered by thinking about moving muscles, in the hopes of providing some control. He survived for three years beyond the five originally predicted. It will never be known if that extension was due to the combinations of experimental drugs that his brothers researched for him in the lab.

Our hearts go out to this brave and special family whose love and caring never faltered, who gave Stephen everything they had to offer and more, and who now must learn to accommodate to the void his absence leaves in their hearts and lives.

At a press conference, Jamie let it be known that his efforts would continue: "Stephen ... gave so much strength to so many. This does not end here. Together with Stephen's spirit continuing to guide us we will take this disease apart and destroy it." From his mouth to God's ears.

Note 2:

To learn more about ALS and Jamie's ALS Therapy Development Foundation, or to send a donation, go to: <http://www.als.net/>