

Hollywood celebrates a medical hero's story



Hollywood loves an underdog. It loves passion. It loves a hero.

It found them all in John Crowley. Crowley, who will serve as the keynote speaker at CISC RP's annual meeting June 14, is the real-life hero behind the just-released film, *Extraordinary Measures*.

Extraordinary Measures, which features Harrison Ford, Brendan Fraser and Keri Russell, tells the true story of a successful young business man whose two youngest children, Megan and Patrick, are diagnosed with a fatal disease. The movie details how Crowley, in a desperate race against time, harnessed his business skills and teamed up with an unconventional scientist to form a bio-tech company focused on developing a life-saving drug – a “special medicine” – to save his children. It brings to life a father's passionate devotion to his children and offers a window into the life-changing power of medical research and the courage of research participants.

While the movie takes liberties with some of the story – the film's Dr. Stonehill is a composite figure representing many scientists Crowley worked with during his journey to find a cure – it is true to the central tenet of the story: John Crowley would not give up.

While Hollywood knows how to make great movies, it's John's story that makes the film so compelling, particularly for anyone familiar with the clinical trial process. John's children were only infants when they were diagnosed with Pompe Disease, a rare and nearly always fatal neuromuscular disorder. As it progresses, Pompe Disease causes muscle weakness throughout the body, particularly in the heart, skeletal muscles, liver and nervous system. If untreated, patients are eventually unable to eat, breathe, speak or walk. Ultimately, many suffer from heart and respiratory failure.

Based on Geeta Anand's book *The Cure*, *Extraordi-*

nary Measures highlights the desperation patients and their loved ones feel as they search for answers. While everyone involved in clinical trials is looking for a solution – a cure, a treatment, a prevention – sick patients and their loved ones feel a unique sense of urgency. Their hope lies with researchers who must ensure the quality of their science by rigorously adhering to protocols and high scientific standards. John's story helps viewers understand what its like to listen to the clock tick. Viewers can feel his billowing frustration as he



encounters repeated delays, setbacks and roadblocks. They can empathize with his profound parental need to “do something” and appreciate the incredible strain the disease puts on his family.

In the end, John's story is also a beautiful testament to hope and the life-changing power of research. Megan and Patrick Crowley are alive today because their father believed in the power of research and invested all his energy in tapping it.